

ASAP Chiari Research Fellow

The ASAP Board of Directors has approved the grant application of Bryn A Martin, PhD, Assistant Professor in the Biological Engineering Department at the University of Idaho.

The one-year research fellowship will be carried out by a fully funded graduate research assistant. The project funding will support the fellow's dissertation that is focused specifically on Type 1 Chiari malformation (CMI). The fellowship will have the potential to be renewed on an annual basis. The fellow will train under the supervision of Dr Martin.

Dr Martin is an expert in CMI research having conducted numerous studies as a principle investigator and completed more than twenty-five peer-reviewed papers in the area of CMI and related cerebrospinal fluid disorders. From 2012-2015 Dr Martin served as director of the world's first research center dedicated solely to Chiari malformation at the University of Akron (Ohio).

Dr Martin joined the University of Idaho in 2015. He also serves as a joint faculty in neurosurgery at the University of Washington and teaches within the WWAMI UW Medical School. In the early 1970s, the University of Washington took on a bold challenge to train and prepare physicians to care for patients and communities throughout the WAMI states, Washington, Alaska, Montana and Idaho. Wyoming joined in 1996. Today, this regional medical education program known as WWAMI, an acronym representing the states it serves, is heralded as one of the most innovative medical education and training programs in the country.

Dr Martin believes the research fellowship will allow them to expand on the previous studies he has completed and assist in developing additional information into the mechanics of Chiari diagnosis, development and progression.

ASAP Syringomyelia /Chiari Fellowship Award

Award Amount
\$10,000-20,000

Purpose

The Syringomyelia/Chiari Fellowship is meant to assist neurosurgeons in the clinical investigation or basic science research of Syringomyelia, Chiari malformation and related disorders. The American Syringomyelia & Chiari Alliance Project, Inc sponsors this fellowship award.

Eligibility

The fellowship is open to all neurosurgical residents and fully trained neurosurgeons at any stage of their careers in the United States. The fellow will spend 6 to 12 months under the direction of a specific sponsor in clinical, translational, or basic science investigation as relevant to Syringomyelia, Chiari malformation and related disorders.

Eligible Expenses

The amount of support will depend on the location and duration of the fellowship. Budget support of up to \$20,000 is available. Detailed budget justification and an account of expenses incurred following completion of the fellowship are required. Residents will not be paid extra salary support that is already covered by clinical residency programs. In addition to the budgeted expenses, the cost of meeting registration and travel (economy airfare reserved at least two weeks in advance) to the ASAP Chiari & Syringomyelia Conference in the year of the fellowship will be reimbursed.

Application Requirements

www.asap.org/index.php/research/fellowships-and-awards/

COLLEGE RESOURCES FOR STUDENTS WITH DISABILITIES

Support, Advocacy and Assistive Technology to Facilitate the Transition to Higher Education

<https://www.affordablecollegesonline.org/college-resource-center/resources-for-students-with-disabilities/>

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Paying for School, Special Tuition Programs & Expert Advice

<https://www.accreditedschoolsonline.org/resources/scholarships-financial-aid-for-students-with-disabilities/>

Thanksgiving

For Barbara and Don White for starting the organization

For every volunteer who has served on an ASAP Board

For every doctor who dedicates time to learning more about Syringomyelia and Chiari

For every nurse who knows there is a physical cause to our symptoms

For every friend who listens and doesn't judge

For every spouse, child and parent for unconditional love

For every donor who makes it possible for ASAP to provide programs and fund research

For hope

For volunteers who promote awareness

For support in every form

ASAP Awareness

On September 9, Lisa Dunton Roy hosted the **4th Annual ASAP Cruisin for CM/SM** in Glenburn, Maine.

Lisa wrote, "Yesterday's 4th Annual Cruisin for CM & SM was a great success! It's not about the amount of donations, number of participants BUT helping with awareness, education & helping others who are affected with these conditions. We met more family members & that makes it all worth it!" Lisa, support group leader for the state of Maine, works hard to improve the treatment of Chiari and Syringomyelia patients in Maine.

Sarah Dyer hosted **ASAP's Cruising for Chiari Motorcycle Ride** on September 15 in Augusta, Maine.

Sarah wrote, "It was a small group of about 20 riders. The weather was perfect making for a gorgeous ride. While my hope was for a larger group, any form of awareness is a movement in the right direction. Fun was had by all and we even raised some money for ASAP."

Sarah has been involved in multiple projects since the first of the year raising awareness and funds.

Contact Information

American Syringomyelia & Chiari Alliance Project

Mailing Address:

PO Box 1586
Longview, TX 75606-1586

Physical Address:

300 North Green Street, Suite 412
Longview, TX 75601-7337

Phone: 903-236-7079

Fax: 903-757-7456

Toll-free: 800-ASAP-282

Email: info@ASAP.org

Staff:

Patricia Maxwell
Patricia_Maxwell@ASAP.org

Jamie Mayhan
Jamie_Mayhan@ASAP.org

Life is 10% what happens to you and 90% how you react to it ...

Stamp Project

ASAP members and friends have been collecting postage stamps as a fundraiser since the early 90s. It is an easy and fun way to make a difference. Stamps are sold to collectors and stamp clubs with the proceeds going to support programs for the Chiari and Syringomyelia community.

Please send cancelled postage stamps that are in good condition (attached to envelope and trimmed with a 1/4 to 1/2 inch border around undamaged stamp). Forever, special occasion and foreign stamps are accepted as well as postcards. Nonprofit, postage meter and presort stamps are not collectable.

Mail stamps to:
Charles Petkevich
ASAP Stamp Project
6202 SW 2nd Court
Plantation, FL 33317



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.

www.ASAP.org

Visit us on the web and be sure to check out our YouTube and FaceBook groups.



A Word From Our President Eric J Berning

Happy Fall!

This is my favorite time of the year. I love the cooler weather, the change of seasons, and the plethora of apple- and pumpkin-flavored items. (The fact that my wedding anniversary and birthday are both in the fall season doesn't hurt either.) As a community, we celebrate September as Chiari Awareness Month, and I find it greatly motivating to see the different ideas, social media "memes," and community outreach being shared and promoted. On a personal level, each September I challenge myself to raise awareness about Chiari and Syringomyelia by daily seeking out others to tell about these conditions and how they affect our lives.

Of course, one of the ways we further awareness and ASAP's mission is through fundraising. But perhaps organizing a big event and soliciting donations is an overwhelming, intimidating task for you. Is there a way to raise money for ASAP without undertaking a major project? Sure! Like many of you, I have a FaceBook account—and, while I do not actively post to it these days, I continue to maintain it as a way of keeping in touch with my "FaceBook friends." Did you know that Facebook has a neat little fundraising option you can use to raise funds for your favorite charity? (Hint, hint: ASAP) I utilized this function for my birthday this year, and found that with very little effort on my part, I was able to raise a few dollars to continue our mission. You can do this too! There are many ways you can passively assist our mission and goals—another option is through Amazon's Smile program, which automatically donates a percentage of your purchase price to the charity of your choice when you shop at <https://smile.amazon.com/>. Go to your Amazon account for details on how to easily set it to support ASAP. These are just two very simple ways that you can help without having to do more than click a button!

The ASAP office can help and direct you with many other ideas and resources to raise awareness and support for Chiari and Syringomyelia. You do not need to organize a huge effort; small efforts help just as much and are incredibly important to our success.

Reach out and let us know if you need assistance in setting up an awareness event, a support group, a fundraiser, or anything else to help raise awareness and provide support to those affected by these conditions.

Planning is underway for the 2019 conference. Locations are being discussed, host doctors are being approached, and details will follow as soon as they get underway. Look for some different options this coming year as we seek to make the conference easier to attend for as many people as possible. The videos from the 2018 conference will be up on our YouTube channel soon. We look forward to having you join us next summer!

Remember to always live within your limits, but to live a life that is limitless!

Gluten Intolerance

Gluten is a protein found in wheat, barley and rye and can cause widespread symptoms, many of which have nothing to do with digestion. Celiac disease is the most severe form of gluten intolerance. However, 0.5–13% of people may also have non-celiac gluten sensitivity, a milder form of gluten intolerance that can still cause problems.

Gluten intolerance can have numerous symptoms. Some of the main ones are listed below. However, keep in mind that most of the symptoms may have other explanations as well.

1. Bloating - Although bloating is very common and can have many explanations, it may also be a sign of gluten intolerance.
2. Diarrhea, Constipation and Smelly Feces - Occasionally getting diarrhea and constipation is normal, but it may be a cause for concern if it happens regularly.
3. Abdominal Pain - Up to 83% of those with gluten intolerance experience abdominal pain and discomfort after eating gluten.
4. Headaches - If you have regular headaches or migraines without any apparent cause, you could be sensitive to gluten.
5. Feeling Tired - Gluten-intolerant individuals are very prone to fatigue and tiredness, especially after eating foods that contain gluten.
6. Depression and/or Anxiety - People with digestive issues seem to be more prone to both anxiety and depression.
7. Iron-Deficiency Anemia - Iron deficiency anemia may be among the first symptoms of celiac disease that your doctor notices.
8. Autoimmune Disorders - Interestingly, having celiac disease makes you more prone to other autoimmune diseases. However, non-celiac gluten sensitivity has not been associated with an increased risk of autoimmune disorders, malabsorption or nutritional deficiencies.
9. Joint and Muscle Pain - Gluten-intolerant individuals commonly report joint and muscle pain. This is possibly due to an over-sensitive nervous system.
10. Leg or Arm Numbness - Another surprising symptom of gluten intolerance is neuropathy, which involves numbness or tingling in your limbs.
11. Brain Fog - Gluten-intolerant individuals may experience brain fog. It involves having difficulty thinking, mental fatigue and forgetfulness.

Vagus Nerve Problems

Nerve damage

Damage to the vagus nerve can have a range of symptoms because the nerve is so long and affects many areas.

Potential symptoms of damage to the vagus nerve include:

- difficulty speaking or loss of voice
- a voice that is hoarse or wheezy
- trouble drinking liquids
- loss of the gag reflex
- pain in the ear
- unusual heart rate
- abnormal blood pressure
- decreased production of stomach acid
- nausea or vomiting
- abdominal bloating or pain

The symptoms someone might have depend on what part of the nerve is damaged.

Gastroparesis

Experts believe that damage to the vagus nerve may also cause a condition called gastroparesis. This condition affects the involuntary contractions of the digestive system, which prevents the stomach from properly emptying.

Symptoms of gastroparesis include:

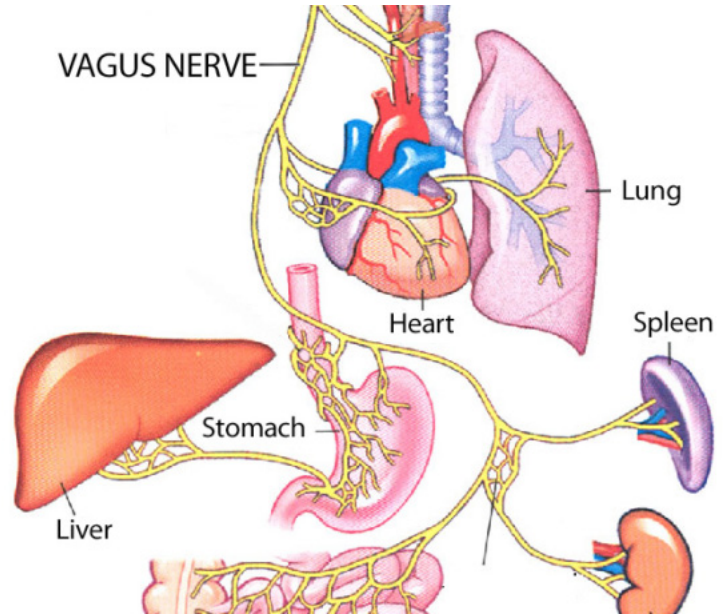
- nausea or vomiting, especially vomiting undigested food hours after eating
- loss of appetite or feeling full shortly after starting a meal
- acid reflux
- abdominal pain or bloating
- unexplained weight loss
- fluctuations in blood sugar

Some people develop gastroparesis after undergoing a vagotomy procedure, which removes all or part of the vagus nerve.

Vasovagal syncope

Sometimes the vagus nerve overreacts to certain stress triggers, such as:

- exposure to extreme heat
- fear of bodily harm
- the sight of blood or having blood drawn
- straining, including trying to having a bowel movement
- standing for a long time



Remember, the vagus nerve stimulates certain muscles in the heart that help to slow heart rate. When it overreacts, it can cause a sudden drop in heart rate and blood pressure, resulting in fainting. This is known as vasovagal syncope.

Vagus nerve stimulation

Vagus nerve stimulation involves placing a device in the body that uses electrical impulses to stimulate the nerve. It's used to treat some cases of epilepsy and depression that don't respond to other treatments.

The device is usually placed under the skin of the chest, where a wire connects it to the left vagus nerve. Once the device is activated, it sends signals through the vagus nerve to your brainstem, which then transmits information to your brain. A neurologist usually programs the device, but people often receive a handheld magnet they can use to control the device on their own as well.

It's thought that vagus nerve stimulation could help to treat a range of other conditions in the future, including multiple sclerosis, Alzheimer's disease, and cluster headaches.

[<https://www.healthline.com/human-body-maps/vagus-nerve>
Medically reviewed by Nancy Hammond, MD on July 31, 2018
— Written by Jill Seladi-Schulman, PhD]

Career Guide for Students with Disabilities

Understanding the ADA, Knowing Your Rights & Finding Disability Resources

<https://www.affordablecollegesonline.org/students-with-disabilities-careers/>

College Students Living with a Chronic Condition

Balancing School and Disease Management, Know Your Financial Aid Options and more

<https://www.onlinecolleges.net/for-students/chronic-health-issues/>

How to Manage Your Medications While You Travel

If you are going on vacation, you do not want to forget your meds. Bringing them along can be complicated, though, especially if you're going overseas. How do you pack your pills? Can you stay on your dosing schedule? Will there be problems with security?

Carry them on

We all know our checked bags may not make the same flight we do. Pack your medication in your carry on for safety and easy access if you need them. The TSA will allow liquid medicine over the usual limit of 3.4 ounces but you must tell an officer at the beginning of the security check. Keeping them with you will also prevent exposing them to extreme heat or cold, which can affect how they work. Never leave medicine in the glove compartment or the trunk of your car. If they need refrigeration just pack them in a lunch bag with an ice pack.

Don't repackage your medication

Make sure your pills and liquid meds stay in their original, labeled containers. Take a copy of the prescription along. Also, bring a letter from your doctor explaining your condition, especially if you are taking a medication you inject or a controlled substance such as a narcotic. This holds true for needles, syringes and oxygen tanks too.

Check the law

Just because a medication is legal in the United States doesn't mean it's allowed in other countries. Before you go abroad, check with the U.S. embassy at your destination to make sure. Take enough to get through the trip plus a little extra. It is a good idea to bring additional meds in case you stay longer than expected. Be sure to think ahead. You may need to ask your doctor for a new prescription and tuck it in your bag.

Be aware of time changes

If you are traveling across time zones, it may complicate your medication schedule. Set an alarm on your smart phone to help you keep the same interval between doses. It may be okay to take meds an hour or two earlier or later but don't double up. Check with your doctor or pharmacist to see how to handle the switch to a new time zone.

Avoid the sun

Remember some drugs can make you sensitive and increase your risk of sunburn. Too much heat can be a problem especially for medicine patches. If you are going to a warm climate, be sure that the meds in your patch will not be released too quickly. Again, check with your doctor. It is great to get away and you need to have fun. It is good for the soul. The right precautions taken before you go can make all the difference. Safe travels.

Molly's 4th Annual Walk & Roll

On September 15 Molly Lichtenstein and family hosted their 4th annual walk to raise awareness in Maryland. Molly works hard every year to make her walk more successful and once again she has surpassed her goals. The event raised over \$30,000.

Sponsors for 2018:

Gold Sponsor

Bretton Woods Recreation Center

Silver Sponsors

Seasons Nursery

Rill Architects

Jeffrey Goodman Company, LLC

Mill Creek Parish United Methodist Church

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Bronze sponsors

TUVA

TKC Global

Adventist Health Care

Mackson

Brass Sponsors

Darnestown Swim & Racquet Club

Keith Gilbert, DDS

thirty-one www.fairfaxbags.com

Proflex Physical Therapy

Colonial Opticians

Friends of ASAP

Law Offices of Steve Gittleson

Healing Hands Chiropractic

Birchwood Lawncare Inc

DontBeKneady.com

Molly's Army 2018



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 and loved ones.

We will send an acknowledgement card to individuals or families when you make a \$5 (or more) donation to the organization. Please indicate whether the gift is 'in honor of' or 'in memory of' and provide name and mailing address of the recipient.

In Honor of Person

Donor

Jacqueline Babitts

Steven & Rosa Babitts

Taryn Gardner

Andy & Arlene Boggs

Greg & Iwana Boggs

ASAP, Patricia & Jamie

Julie Jarvis

Addison Graves

Kristi Graves



In Memory of

Donor

Glen "Buz" Tarpley

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Merna Miller

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Daniel Mullens

Diane Mullens

Diane Strauser

Michelle Strauser

Beverly Bassett

Donald Bohlken

Carolyn Rebecca Lockett

Andy & Arlene Boggs

Don & Barbara White

Julie Jarvis

In Sincere Gratitude

by Julie Jarvis

First there is *purpose, reason, direction* and *life circumstances*.

Find that person or persons to create an avenue for all to come together for a common goal. Then go forward and help create new life for the future of those in need. Needs of course are varied and interests in reaching their objective.

Go. Do. Be. Let no one or nothing encumber the goals set before you.

Faith first, prayer, trust and love will guide you.

Purpose and *reason* began when Don and Barbara White met with a small group, including people from the Bobby Jones Open in Michigan, all with the same goal of helping people with Syringomyelia. The Whites formed the American Syringomyelia Alliance Project (now the American Syringomyelia and Chiari Alliance Project).

Together united this group shares knowledge in creating a cure and new life for those with Syringomyelia and Chiari. This helped to produce the 2018 International Symposium. 30 years to this point in time, what a blessing!

Faith was first, then prayer, trust and love were their guides.

Honoring all whom helped to make these 30 years possible.

2018 ASAP Chiari & Syringomyelia Conference Videos

Available Online

<https://www.youtube.com/channel/UCJHul2aTWLIjLBUulsJSWvg/videos>

or

Go to www.asap.org and click on the YouTube icon in the upper right corner which will take you to our YouTube channel. Click on videos in the menu bar.



Thank you to all our volunteers who have made it possible to serve the Chiari and Syringomyelia community for 30 years.

"Thank You for Supporting ASAP!"

Let us hear from you, update your contact information.

Name _____

Address _____

City _____ State _____ Zip _____

Email _____ Phone # _____

☐ Yes, I would like to continue receiving the newsletter.

☐ No, please remove me from your mailing list.

Your support makes a difference in the lives of thousands. Please help us to continue our programs and research funding with a donation today. Every dollar counts!

☐ Check enclosed payable to ASAP, Inc. – You can also make your donation online at ASAP.org

Credit Card ☐ MasterCard ☐ Visa ☐ Discover ☐ American Express

Card # _____

Name of Cardholder _____

Signature _____

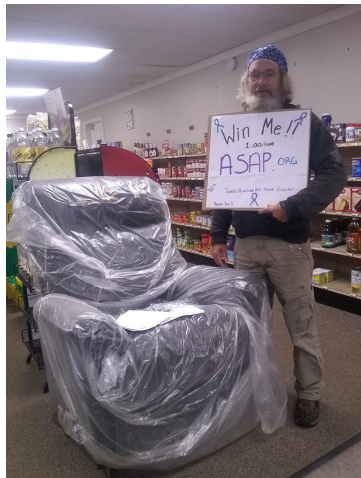
Expiration Date _____ Security Code _____ Amount \$ _____

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

Chiari Awareness Month Activities

Congratulations to Roy, the winner of the month-long raffle for CM awareness held in Glenburn, Maine.

The event was held by the ASAP Maine Chiari & Syringomyelia Support Group. Lisa Dunton-Roy wrote, "The winner was overwhelmed to say the least. He kept saying, 'I never win anything'. He thanked us & wished us nothing but the best in our efforts. He had never heard of these conditions until the raffle. We reached a lot of people to spread awareness & education running it for a month."



In September Jamie Mayhan posted facts about Chiari on the ASAP FaceBook pages daily. On average they reached 10,000 people each post with the most popular reaching 20,000. Many members also posted and shared a variety of information to help spread awareness.

Thank you to everyone who helped spread awareness about Chiari during September.



Sharing awareness in Glenburn, Maine



Chiari Ride in Augusta, Maine

ASAP's Mission: to improve the lives of persons affected by Syringomyelia, Chiari malformation and related disorders while we find the cure.

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ASAP Connections

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 quarterly for ASAP members. Your contributions of articles, letters, and photos are encouraged. The editor reserves the right to edit any article in order to accommodate space.

Email: Patricia_Maxwell@ASAP.org

Mail: *ASAP Connections*
PO Box 1586
Longview, TX 75606

ASAP Connections Editor: Patricia Maxwell