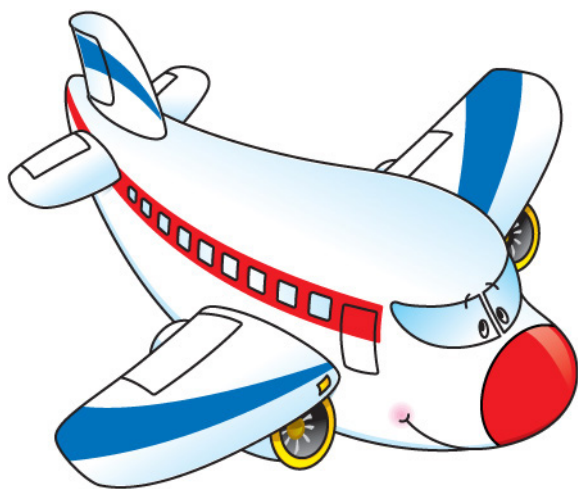


ASAP, envisioning a world without the devastating effects of Syringomyelia, Chiari and related disorders.

Summer Travel

Whether you're traveling with a permanent or temporary physical disability, the challenges remain the same. The U.S. Department of State (<https://travel.state.gov/content/travel/en/international-travel/before-you-go/travelers-with-special-considerations/traveling-with-disabilities.html>) is a good general resource. The Americans with Disabilities Act (ADA) details what accommodations should be made for those with an impairment. Even though U.S. hotels, transportation, and cruise ships sailing in U.S. waters are required to be ADA-compliant, don't assume that they will be. Check before you travel to discuss accommodation for your specific needs.



Preparing for your trip is critical:

- Consult your travel agent, hotel, airline, or cruise ship company to learn about services during your trip and your destination, including specific requirements for service animals.
- Call the Transportation Security Administration's (TSA) helpline for travelers with disabilities and medical conditions at 855-787-2227 (toll-free) to request assistance with the security screening process, or check TSA's website, TSA Cares (<https://www.tsa.gov/travel/passenger-support>). They can answer questions about screening policies, procedures, and the security checkpoints.

Service animals:

- Talk with your vet about tips for traveling with your service animal.

- Make sure your hotel will accommodate your service animal.
- Confirm with your airline whether it has any additional requirements.

Assistive Equipment:

- Research whether the airline follows specific policies for devices such as wheelchairs, portable machines, batteries, respirators, and oxygen. The airport/security screening in the departing and arriving airports may also have specific policies.
- Research the availability of wheelchair and/or medical equipment providers and repair services.
- Consider the following regarding wheelchairs:
 - Manual vs. power (ease of loading, storing, etc.)
 - Supplies such as wheelchair tires, tubes, and patch kits – consider bringing extra as these may not be available at your destination
 - Gate checking – always gate check your wheelchair and retain the receipt
 - Airline policies on damaged equipment

Medical Consideration:

- Carry medical alert information and a letter from your health care provider describing your medical condition, medications, potential complications, and other pertinent medical information.
- Carry sufficient prescription medication to last your entire trip, including extra in case of delay. Some that are legal in the United States are illegal in other countries.
- Always carry your prescriptions in their labeled containers, not in a pill pack.
- Pack medications in your carry-on luggage. Avoid packing medications in checked luggage in case your luggage is lost or delayed.
- For medications that require refrigeration, consider how to best transport them (i.e., use an insulated bag; request a hotel room with a small refrigerator, etc.)
- Consider bringing extra supplies such as incontinence supplies, diabetes test strips, hearing aid batteries, etc., as these may not be available at your destination.

Ulrich Batzdorf, MD

Dr Ulrich Batzdorf is a pioneer in the modern treatment of Chiari (CM) and Syringomyelia (SM). An organizing member of the Medical Advisory Board, he has been involved with ASAP for over 30 years. A frequent speaker at the ASAP annual conference, he will be lecturing at the 2021 meeting in Chicago.



Professor and Executive Director of Spinal Neurosurgery, Dr Batzdorf's primary clinical and research focus is on the treatment of Chiari malformation and Syringomyelia. An attending physician at UCLA Medical Center since 1975, Dr Batzdorf is the author of multiple articles and books on CM/SM. He is considered a leader in the development of diagnosis and surgical treatment.

<https://asap.org/conferences/2021-conference/>



In Memory of Barbara White

20 May 1946-10 December 1991

As we travel through our journey upon this earth many people touch our lives, but few make an impact like Barbara White. To know her was to have a friend. She had a way of putting a person at ease. No matter how depressed someone was when they contacted the ASAP office, after talking with Barbara they had a new lease on life.

It was not always easy. Some days her head hurt so bad she could hardly talk, but would dig down and pull up that inner strength of hers and do what she felt had to be done. It was important to Barbara that her new friends not see what she was going through. She always had hope and wanted others to share it with her.

She was only human; there were more bad days than good but she always tried to hide it. Her reward was each new member who knew they were not alone in their struggle. She knew that each person who knew about Syringomyelia and Chiari was a step closer to reaching ASAP's goals.

Catherine S. wrote: I first heard from Barbara in July of '88 when I was in the rehabilitation unit in St. Michael's Hospital after I had spinal surgery. I returned to my room from therapy one day and there was a letter from Barbara. I was so excited as I read the letter. I learned about ASAP and Barbara was the first person I had heard from with SM and was going through the same thing as I. She was an inspiration, always so full of life, a very courageous person.

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

Summertime and the living is easy, or so the saying and song go. Weather has a significant effect on all of us in some way or another. Some of you know I originally hail from Ohio, but now live in the great state of Texas. One of the reasons I choose to live in the south is the weather. Cold temperatures are just downright uncomfortable for me. They make every bone in my body hurt, and half a year with the cold is too much. I do not like it. Do I enjoy the extreme heat and humidity? Well, not always, but for me it sure beats the cold. How does the weather affect you? Some of us are like walking barometers. With the sensitivity in our CSF, we can tell when a storm is moving in or if there is a significant change coming. Sometimes I find that my body is more reliable than the local weather guy on the news.

Depending on where you live, we all must deal with some sort of weather issue (except you lucky folks in San Diego; your weather is near-perfect!). I have lived a lot of different places throughout the Midwest, West Coast, and South. One of the most interesting and renowned cities I've had the opportunity to live in is Chicago—which just so happens to be where we will be holding the 2021 ASAP Conference this October. The Windy City is unique, weather-wise. While they do get four seasons, it can feel like summer and winter are the longest. When I lived there I affectionately referred to the “six weeks of awesome Chicago weather”: three at the end of May/beginning of June (before the heat) and three at the end of September/beginning of October (before the cold). Of course, those six weeks of perfect weather were my body's favorite.

Well, guess what: the 33rd Annual ASAP Conference is scheduled for that first week of October (10/5-10/9)! Now, I cannot guarantee that my weather predictions will play out as accurately as I remember them being, but what I can promise you is that Chicago is an amazing city to visit, with

a plethora of sights, sounds, and tastes to enjoy. One of the many features of “Chi-town” is that it is situated directly on the lake front, with a most stunning skyline. The ASAP Board and conference planners have decided to take full advantage of that feature by scheduling our first speakers on Wednesday afternoon, followed by a dinner cruise on Lake Michigan as our opening reception for all in attendance. Thursday and Friday will be full days of speakers, with an open evening Thursday to check out what the city has to offer. We will host a banquet Friday night, then a final morning of speakers on Saturday to close things out. We hope to have the agenda of speakers/topics published by the time this newsletter reaches you. Be sure to check our website www.ASAP.org for more details.

We look forward to seeing you in person in Chicago in October! Please note, we are also looking into the possibility of offering a virtual platform for those who are not comfortable or able to travel just yet. Again, stay tuned to our website for more information.

Wherever you are, enjoy the “lazy days” of summer and the warmth of the sun. Remember that “you may have to live a life within limits, but you can still lead a limitless life!” Lead limitlessly!



Staying Cool When It's Hot

Summer is here and it's going to be a scorcher. While hot weather is nice, and you've never looked better than with that killer tan, it's crucial to know how to keep yourself cool. Heat stroke and hyperthermia are very real things. When your body produces or absorbs way too much heat, it can cause some serious damage.

Without further ado, here are some tips on how you can keep yourself cool, even when it's heating up.

Drink Lots and Lots of Water

Hydration is key when your body is trying to regulate temperature. Sweating is your body's way of cooling you down. Contrary to popular belief, while iced water is your safest bet in cooling you down, things like pop or energy drinks will also help you cool down. Any liquid is better than no liquid. Having said that, make sure you're not drinking coffee, as it's a diuretic and can have dehydrating effects.

Avoid the Sun between 11 AM To 2 PM

The sun is the hottest between 11 and 2, and sunburns are most likely to happen during that period. Limiting your exposure will limit your chances of overheating. If you can't get around not being outside during those hours, make sure you dress appropriately and hydrate.

Dress Appropriately

Wear loose, breathable clothing and footwear that won't leave your feet sweaty. Hats are also crucial for blazing hot weather, keeping you cool by providing shade. Sunglasses will protect your eyes from damaging UV rays.



Refrigerate or Freeze Your Bedsheets

It sounds crazy but once you try this trick, you'll wonder why you haven't thought of it before. Place your bedsheets in your fridge or freezer for a half an hour before you sleep, and you'll never have trouble falling asleep because of the heat again. Also consider investing in soft gel packs that you can place underneath your sheets, or tucked between your legs (wrapped in a tea towel).

Cool Down Your "Hot Zones"

Pressure points (ankles, behind the knees, wrists, neck, temples and elbow bends) are your secret key to happiness! Applying a little ice pack or a bottle filled with iced water



will help you cool down immediately. You can find all kinds of items from cooling cuffs to neck cooling bandanas.

Get Spicy

Weird but true: spicy foods actually help you cool down. They increase your blood circulation, which in turn gets you sweaty. And sweating cools you down when the sweat cools down. If you cannot sweat, you probably should not try this one.

Eat a Popsicle

It was the best way to cool down when you were a kid, and nothing has changed.

Enjoy a Smoothie To Cool Down

Don't feel like a popsicle? An ice-cold smoothie will bring your temperature right down, not only because of its chilly factor, but also because it'll keep you hydrated.

Strawberry Banana Smoothie:

In a blender, pulse all ingredients together until smooth.

- Frozen strawberries
- Banana
- Milk (Any type of milk will work for this recipe — cow's milk, almond milk, oat milk, you name it).
- Ice (However much is needed to achieve your desired smoothie consistency).

Too thick, add more milk or ice, too thin, add more strawberries.

Consume More Salads

Choose chilled items for lunch instead of hot soup. Salads are a great option, and you'll also be feeling healthier than if you downed a burger for lunch.

Enjoy your summer and be safe.

Lilly's Story

by Jillian Hamm

Lilly's story began on July 18, 2008. She was the seventh child in our family of 8 children and adored by everyone. As a toddler, Lilly was in and out of the hospital with undiagnosed illnesses. By the age of 7, she was hospitalized with Meningitis, and they determined that she had Chiari and Syringomyelia.



I had been diagnosed with Chiari and EDS several years prior to us discovering Lilly had it. After Lilly's diagnosis we then found out that several of her siblings are also affected.

We were referred to a neurosurgeon, and our nightmare began. Lilly had her first surgery, we had no idea what to look for and we trusted a well-known hospital. There was no testing for comorbidities, and we soon found out that there should have been.

We next sought out a specialist who only works with patients with these issues, and her subsequent surgery (spinal) was scheduled a few months later. Soon after her spinal surgery, she required a cervical fusion and then a VP shunt. Multiple shunt revisions and tethered cord releases were now her life. Lilly had IV fluids numerous days a week for Dysautonomia, medications for her Mast Cell disease, and Immunotherapy for her weakened immune system. We tried everything, constantly feeling like we were fighting an uphill battle. But through it all she remained positive and had a smile that would light up a room and eyes that would melt you. She adored animals, especially her dog Cookie. She loved Jesus, her family, Mario Kart, Minecraft, cupcakes, and the color red.

In early 2020 after a decent time without hospitalizations, Lilly's shunt failed while we were managing things at home. She now faced another surgery in June. We thought nothing of it; heck, she had been through so many revisions we just wanted her to get through it so she could spend the summer swimming, another favorite of hers. June 4th is the last day my girl walked. The revision didn't go well, and she ended up with a brain bleed. It was sudden and traumatic. We lost our Lilly in the early hours of June 8, and our world shattered. There is no way to describe the nightmare our family is going through not having Lilly here. We had an angel in our family, and we miss her beyond words.

May Her Memory Be Eternal.

"Her absence, like the sky, is spread over everything."

C.S. Lewis

Fundraising News

ASAP's 1st Annual Walk and Roll Honoring Lilly took place July 17 in La Crosse, Virginia. **Thank you** to Lilly's family and friends who raised over \$5,000 for research and programs to benefit the Chiari and Syringomyelia community.

ASAP Virtual Auction

We've received quality donations for our 2021 online auction. Thank you to those who have contributed to date. However we still need more items to make this work. Suggested items include: re-gift a new item, handmade jewelry and crafts, artwork, designer purses, airline points, and gift cards.

A form for donations is available on our website at [ASAP.org](https://www.asap.org). On the homepage, scroll down to **2021 ASAP Virtual Action** and click on "Download donation form."

Need a form mailed to you? Just email, call or write the office and let us know. You will find contact information for the office on page 6 of this edition. Be sure to include the completed form with your contribution. If you would like to solicit donations from various companies, we can provide you with a donation letter to assist you. Please contact Patrice Schaublin.

The online auction site will be live in early October, so be sure to check our website for the link.

If you have items you would like to donate (any time of the year) please mail them to:
ASAP, 300 N Green St Ste 412, Longview Texas 75601.

I stopped explaining myself when I realized people only understood from their level of perception.

Tip of the Day

Exercise to be fit, not skinny,

Eat to nourish your body,

Always ignore the haters and doubters...

You are worth more than you realize.

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 person you would like to honor.

In Honor of Donor

Jacqueline Babitts

Steven & Rosa Babitts

Michael Kirlin 31st

birthday

Dennis & Diane Kirlin

In Memory of Donor

Betty Burke

Dale Burke

Helen Haseltine

Karen Young

Melissa Ruth

Donald & Lisa Smith

Jennifer Burkhardt

Robert Bowers

Ramona Johnson

Family & Friends

Rosemary McPartland

Alice Sinclair



Volunteers Needed

We are looking for those who are passionate about our cause to serve on the Board of Directors. Meeting are held via zoom with on site meeting during annual conference. Directors are the governing body for the organization and serve a three-year term.

We are seeking someone with accounting experience who would like to serve on the Board and fill the position as Treasurer. This position would require you to review financial statements, develop a budget and approve expenditures.

Interested parties should contact Eric Berning via email at Eric_Berning@ASAP.org for an application.

We are always looking for volunteers to serve on committees, help with fundraising, awareness and organize support groups. Complete the volunteer form on our website.

<https://ASAP.org/volunteer/>

Or you can contact Patrice Schaublin.

ASAP Contact Information

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

Patrice Schaublin,

Executive Director

Patrice_Schaublin@ASAP.org

Phone: 585-747-9651

Jamie Mayhan,

Programs Director

Jamie_Mayhan@ASAP.org

Patricia Maxwell,

Operations Director

Patricia_Maxwell@ASAP.org

ASAP Database

The ASAP database is maintained through Blackbaud, a cloud computing provider that serves nonprofits, foundations, corporations, education institutions, healthcare organizations, religious organizations, and individual change agents.

Inquiries are added to the database when they contact the organization. If they request the newsletter either digitally or hardcopy, you are considered a member. On occasion, email blasts are sent to all contacts. You have the option to opt-out at any time. However I have noticed that many emails are not delivered.

If you are interested in receiving information from ASAP please add info@ASAP.org to your contact list. On the next page is a form to ensure the information we maintain is accurate and up-to-date. Please take a few moments to complete the form and return to the ASAP office. Thank you for being a part of the American Syringomyelia & Chiari Alliance Project. Together we can make a difference.

All I'm Asking for Is A Little Respect

by Patricia Maxwell

Disabilities can be hard but is society making it even harder? to you is over the line, effectively blocking your ability to load your wheelchair.

My dad was an amputee. His left leg was removed following a motorcycle accident before he married my mom. I never thought of him as disabled. He was my hero. He taught us to swim, ride a horse, coached my brother's baseball teams and ran a business, everything and more than many fathers. He never let his loss stop him from doing whatever he wanted to do. This is probably why I never realized he was disabled until my late teens.

Most people experience hardships directly and indirectly related to their disabilities. But many find that most of these hardships come from other people and the environment they live in, not the disabilities themselves. Indirect hardships imposed by other people's lack of consideration can sometimes be the biggest obstacle a person faces.

Yes there are days when you just cannot get out of bed, or find yourself cancelling an event due to your symptoms. But what about those days when you have to get groceries, and the marked parking space is occupied by someone without a handicap plaque. Or you parked your van at the doctor's office and when you go to leave the car parked next

Disabled people endure and have to work through many issues, but much of it is entirely unnecessary pressure from the outside. Disability hardships are real, but they don't have to be, and everyone can help reduce them by the way we treat one another. It is not a luxury to park next to the entrance; it is a necessity for those who have the right to park there.

It's also important to note that a lot of the emotional and inspirational "takes" on disability that are so popular in social media memes and motivational writing depend on this mistaken and corrosive notion that disability is fundamentally a natural tragedy to be overcome. It's not. It's also off-base and unhelpful to casually poach disabled people's hardships and experiences, run them through a simplistic filter, and use them as all-purpose motivators and object lessons for human courage and perseverance.

Disability isn't a single, definable experience, and disabled people aren't here to be anyone's walk-up call.

"ASAP Member!"

We are in the process of updating our database.
Please let us hear from you to ensure your information is current.

Name _____

Address _____

City _____ State _____ Zip _____

Email _____ Phone# _____

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

☐ I have ☐ Syringomyelia, ☐ Chiari malformation, ☐ other related disorder _____

☐ I have a ☐ child or ☐ family member with the disorder.

☐ We have multiple family members diagnosed with _____

☐ I am interested in participating in ASAP-sponsored research.

☐ Please remove me from your mailing list.

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



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

ASAP Board of Directors

Eric J Berning, President
John Caemmerer, Vice-President
Annie Chapman, Treasurer
Michele Raye, Secretary
Jeni Adair
Paolo Bolognese, MD
Brian Dlouhy, MD
Gerald Grant, MD FACS
Robert Keating, MD
Molly Lichtenstein
Richard Simon

ASAP Medical Advisory Board

Robert Keating, MD - Chair
Children's National Medical Ctr
Ann Berger, MD
National Institutes of Health
Gerald Grant, MD - Research Chair
Stanford Medical Center
Ian Heger, MD
Medical City Children's Hospital
John Heiss, MD
NIH/NINDS
Bermans Iskandar, MD
University of Wisconsin-Madison
Roger Kula, MD
Neurological Surgery, PC
Cormac Maher, MD
Univ of Michigan Health Systems
Arnold Menezes, MD
Univ Iowa Hospitals & Clinics
John Oro, MD
Colorado Chiari Institute
Erol Veznedaroglu, MD
Drexel Neuroscience Institute



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.

Mail: ASAP Connections
PO Box 1586
Longview, TX 75606

Editor: Patricia Maxwell
Email: Patricia_Maxwell@ASAP.org