

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

## **ASAP Chiari & Syringomyelia Conference 2023**

### **Meet Our Conference Host**

Michael Levy, MD, PhD, is chief of pediatric neurosurgery at Rady Children's Hospital-San Diego and UC San Diego School of Medicine and a professor at UC San Diego School of Medicine.



In 2002, he was recruited to develop a Pediatric Neurosurgical Center of Excellence at Rady Children's and a pediatric neurosurgical fellowship at UC San Diego. Currently, Dr Levy is the director of UC San Diego's Pediatric Neurosurgical Fellowship Training Program and its pediatric neurosurgical international fellowship.

Dr Levy's expertise lies in the treatment of complex pediatric brain tumors and cerebrovascular malformations. He is also involved with the design and utilization of endoscopy and three-dimensional imaging technologies to facilitate surgery.

Along with his clinical expertise, Dr Levy is actively involved in research and is widely published, with more than 200 papers appearing in peer-reviewed literature, seven books and more than 60 book chapters. Additionally, he is currently on the editorial boards of 16 peer-reviewed journals, including Neurosurgery, Journal of Health Communications, World Neurosurgery, Frontiers in Pediatrics and Journal of Neurosurgical Sciences.

Dr Levy's professional memberships include the Society of University Neurosurgeons, the American Academy of Neurological Surgery and the American Society of Pediatric Neurosurgery, along with Alpha Omega Alpha (Medical Honor Society), the American College of Surgeons, the American Association of Neurological Surgeons, the Congress of Neurological Surgeons, Joint Section of Pediatric Neurosurgery and the WHO Global Initiative for Emergency and Essential Surgical Care.

When not practicing medicine, Dr Levy works with the National Football League as an unaffiliated sideline physician and for the NFL Players Association as a surgical consultant.

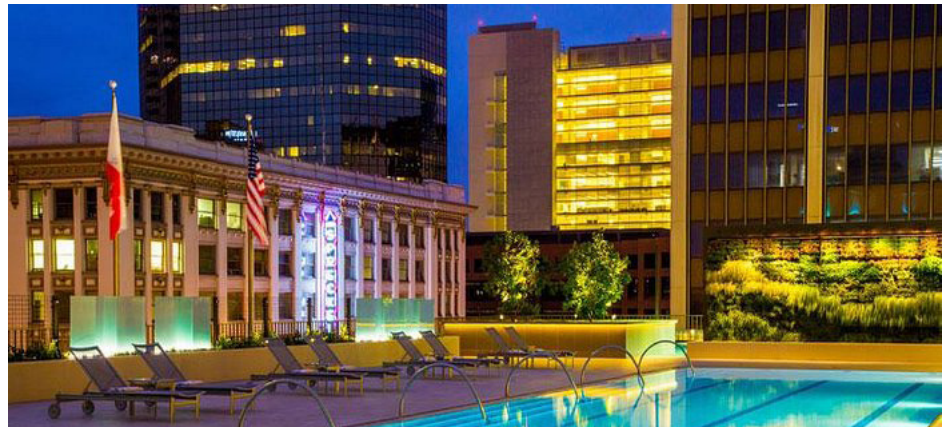
### **Conference Venue**

The Westgate Hotel features old-world European luxury. The common space showcase crown molding, large chandeliers, wide carpeted staircases and elegant curtains draping the floor to ceiling windows. Spacious guest rooms offer either a harbor or city view. Guest will have access to the modern fitness center, spa and rooftop pool.

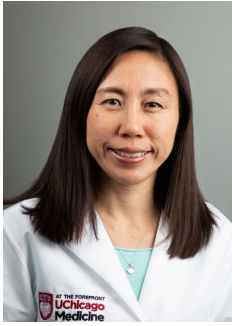
The hotel is located on Second Avenue in downtown San Diego just minutes from the airport. Situated between the Gaslamp Quarter, Little Italy and Petco Park, the area offers more than 150 dining and shopping options.

### **Reserved room block ends July 6.**

Take advantage of our group discount! The Westgate has given ASAP conference attendees a discounted rate of \$199 plus tax per night. In honor of our 35th anniversary, ASAP will provide attendees with a \$35 voucher per night during the conference reducing the nightly base rate to \$164. Individual attendees must make their hotel reservations directly with Westgate reservations at 800-522-1564 or through the hotel portal on the ASAP website. If you need ADA accommodations contact the hotel by phone to make reservations.



## ASAP Board Welcomes New Director



Carina Yang, MD

Vice Chair of Diversity & Inclusion  
Faculty Director of Fellowship  
Accreditation, GME  
University of Chicago Medicine

A board-certified radiologist/  
neuroradiologist, Dr Carina Yang is  
an Associate Professor of Radiology  
and serves as the Director of Pediatric  
Neuroradiology, with a focus on diagnosing

and characterizing the full scope of head, brain, spine and  
neck conditions. Dr Yang is an expert in interpretation of  
neuroradiological computerized tomography (CT) and magnetic  
resonance (MR) examinations, and promotes techniques  
for pediatric patients to minimize radiation exposure and  
performing testing without the need for extended sedation.

She most recently was selected as a Senior Faculty Scholar in  
the Bucksbaum Institute for Clinical Excellence. She also has  
great interest in promoting neuroradiology education to trainees  
and practicing radiologists on a global arena, with past invited  
visiting professorships to locations such as Newfoundland,  
Canada, Hong Kong, as well as Gwalior and New Delhi, India,  
in part with funding from two University of Chicago Provost's  
Global Faculty Awards. She was selected as the 2019 Anne  
G Osborn American Society of North America International  
Outreach Professor to Ethiopia, and most recently traveled  
to Trinidad for additional volunteer pediatric neuroradiology  
teaching. She hopes to continue to further her worldwide  
educational endeavors at new upcoming sites.

## ASAP Celebrates 35 Years in San Diego July 26 – 28, 2023

Join the American Syringomyelia & Chiari  
Alliance Project Medical Advisory Board and  
conference host, Michael Levy, MD, PhD

### Registration:

- Adults 16+: \$175 each
- Children ages 5-15: \$65
- Family pack: two adults and two children:  
\$425
- No charge for children under 5, over 15  
years must register as an adult.

### Registration Includes:

- All lectures Wednesday afternoon through  
Friday afternoon
- San Diego Zoo tour and dinner  
(Wednesday evening after 4:00 PM)
- Kids program: Thursday and Friday
- Breakfast Thursday and Friday
- Cocktail closing reception Friday afternoon

### Other Options:

- Day Rate - Thursday & Friday: \$50.00  
(includes breakfast and lectures)
- Zoo Excursion: \$65 (visitors not attending  
conference)

## 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](http://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*

### Why Me?

Now that is a question I imagine all of us have asked ourselves at one point or another. Why me, why was I born with these disorders, why do I have to deal with these issues? The answer is, simply, because you can handle it. “But I’m not ‘handling it’...I’m struggling.” Yes, I get that it is a struggle—every day will be. You WILL have bad days; you WILL have good days. But what you have are days, hopefully many of them! Use them before they are gone.

Honestly, it stinks having these conditions and disorders. It’s the truth. There is so much we cannot or should not do. Growing up, I hated the cold—it got down into my bones and I was utterly physically miserable just being outdoors—let alone in the snow—during wintertime (that is one reason I live in Texas now). But I led what would be considered a normal childhood; my Chiari and Syringomyelia were not discovered until I was 37 years old. For many years I had no idea one might be related to the other.

Why me? From early childhood, I was small, very small. I did not enjoy any sort of “growth spurt” until well into my later college years. As a high school sophomore, I was 4’ 10” and 68 pounds soaking wet! I was way too small to play sports, and way too uncoordinated to even think about it. I did wrestle my freshman year of high school, but at my slight size I only got 2 matches the whole season and had to wrestle way above my weight just to get those (ending up 1-1 in my entire illustrious wrestling career).

Why me? Not having much success with athletics, I opted to join the theater, as my high school planned an amazing program for the spring musical. Lo and behold, I scored the lead in the musical Oliver! While I was “waif-like” in stature (and thus perfect for the character), I was mature enough to carry the production. Never one to sit around, and always finding a way to challenge my “shortcomings” (so to speak), I also kept myself busy serving 3 years in student government, and was the first male in the history of my college to be elected class president. So, again, I ask: why me? Because I stepped out of my comfort zone and tried something different.

In 2010, I joined an ASAP support group here in Cypress, Texas, and met a mother with two sons who’d been diagnosed with Chiari. She was worried about what their lives might be like, growing up with such a troubling

condition. I definitely understood her fears and her struggles with the “unknown,” but in thinking about it, I realized a simple truth: I was born with Chiari, I grew up pretty normal despite hurdles here and there, and most of all, I survived. Although I had issues, I did not know why at the time—I just figured that’s how I was made. I adapted. I had no firsthand experience about what life might be like otherwise, no knowledge that a lot of my neurological issues, pain, and annoyances were not, in fact, “normal.” I didn’t realize most other people weren’t experiencing my same issues. It really wasn’t until I became more aware of the signs and symptoms of these conditions that I realized I had been experiencing these things for as far back as I could remember, but just attributed them to who I was and how I was made. And truthfully? Figuring out how to overcome those roadblocks have helped make me who I am today. The circumstances I went through as a child, young adult, and now a middle-aged man all helped form my character and personality—and, importantly, have led me to do what I do today.

Why me? Because I get it. Because, sometimes, I am able when others in my situation are not—but I can understand and relate. Because those of us with the ability to be an encouraging example to others need to be just that. I hope that the mother I met in the support group years ago could look at me and perhaps find hope that her children, too, could tolerate the issues and still thrive. And in my current role as President of the Board of Directors, my desire is that you in the ASAP community can rest assured that there are several of us with the same conditions as you doing our utmost to look out for our organization’s best interests and seeking ways to maximize ASAP’s effort to reach more people with information, hope, support, and fellowship.

Why YOU? Because we need you! As much as we love what we do, the Board and I cannot serve endlessly—we are going to need others to also step up and serve. I need those who “can,” to do. Be an example for others. Provide hope and inspiration for those with our conditions, so they will realize that they, too, provide value and can lead the way to a better future for us all. Reach out to me if you want to serve. Let’s have a conversation! That’s why!

As always – Remember that you may have to live a life within limits, but you can still lead a limitless life!



# ASAP Annual Conference

## Frequently Asked Questions

### ***Lodging***

#### **What is the name of the conference hotel?**

The Westgate Hotel  
1055 Second Ave  
San Diego, CA 92101

#### **What is the room rate?**

ASAP receives a discounted rate of \$199 plus tax per night with no resort fee. In honor of our 35th anniversary, ASAP will provide a \$35 voucher per night during July 26-28. The final base price per room is \$164. Price will be adjusted during check-in. Individual attendees must make their hotel reservations directly with Westgate reservations by phone at 800-522-1564 or through the hotel reservations portal.

#### **When is check-in and check-out?**

- Check-in time is 4:00 pm local time
  - Check-out is 11:00 am local time
- Special arrangements can be made for early check-in or late check-out based on availability.

#### **What is the last day to reserve a room at the discounted rate?**

Reserve your room by July 6, 2023 to receive the discounted rate. A limited number of discounted rooms are available on a first come first served basis.

#### **Do I have to stay at the conference hotel?**

No, but you will miss out on ASAP's significantly discounted room rate. Staying at the Westgate offers the convenience of being near the conference proceedings and gives you the opportunity to spend social time with other attendees.

#### **What features are included in the waived resort fee?**

- In-room Wi-Fi
- Access to AquaVie Fitness + Wellness Club including:
- 40,000 square feet of cardio, exercise and strength equipment by Technogym and Precor
- AquaVie group fitness classes
- 10% discount on all treatments at AquaVie Spa
- Saunas and steam rooms
- Rooftop gym
- Heated rooftop pool with poolside food and beverage service
- 2 bottles of water in the guest room upon arrival

#### **Are ADA accommodations available?**

Please contact the hotel by phone for special accommodations per ADA guidelines. Please let ASAP know if you have any issues with this.

#### **When does the conference end?**

The conference concludes with a cocktail hour following the final session on Friday afternoon.

### ***Travel***

#### **What airport serves the area?**

San Diego International Airport (SAN) See more info on the San Diego Tourism page: <https://www.san.org/Travel-Info/FAQs>

#### **What personal transportation is available?**

- Uber and Lyft
- Rental Cars
- Off-airport rental car agencies are served by free shuttle service from multiple locations throughout the terminals.
- Ride Share  
Several companies offer Ride Share services at San Diego International Airport. Travelers can be dropped off curbside at both Terminal 1 and Terminal 2.

The hotel is less than 10 minutes from the airport. The Westgate does not provide airport shuttle service.

#### **What public transportation is available?**

Travelers headed to and from San Diego International Airport can connect with Amtrak's Pacific Surfliner and the COASTER at Amtrak's Santa Fe Depot train station downtown by using Metropolitan Transit System Route 992, which operates between 5:00 a.m. and 11:30 p.m., every 15 minutes on weekdays and every 30 minutes on weekends and holidays.

The COASTER operates 365 days a year, seven days a week, with trips throughout the day to Old Town and North San Diego County. Tickets may be purchased at ticket vending machines on the Santa Fe Depot station platform, online at GoNCTD.com, or via the COASTER Mobile App.

#### **What parking is available?**

Westgate valet parking is available for \$45.00 per night for overnight guests.

#### **Public Parking Garage**

Address: 1050 Columbia St, San Diego, CA 92101  
Phone: (619) 814-4200)

#### **One America Plaza**

Address: 501 W Broadway, San Diego, CA 92101  
Phone: (619) 236-8752

## Special Event Happening at our Conference

Wednesday evening ASAP conference attendees will be able to explore the world-famous San Diego Zoo. The exhibit houses 4000 animals of more than 650 species and subspecies on 100 acres.



Relax and enjoy a narrated, round-trip 35-minute adventure through Zoo grounds on a double-decker accessible bus.

To complete the evening a plated dinner will be served in the TreeTop room.



Registered attendee can purchase additional tickets for the zoo event for family members not registered for the conference. These tickets must be purchased in advance.

*When life gets too difficult to bear,  
your inner strength can help  
you fight your toughest battles.*

## May is Syringomyelia Awareness Month



Wow, it is hard to believe ASAP is celebrating 35 years of providing services to the Chiari and Syringomyelia communities. I wish Don and Barbara were here to see their dream's progression. I know they would be proud.

The advances in medicine have changed greatly in 35 years. Physicians understand more about the dynamics of Chiari malformation and its treatments. But we still have a long way to go where Syringomyelia is concerned.

ASAP was two years old, when I entered the picture. I only knew Barbara for a short time, but she was one of those people with whom you instantly fall in love. Her goal was to find answers so the children would not share her experiences. It is with heartfelt thanks to those who continue to search for answers that we continue to move forward.

Each May we ask our member to make an extra effort to spread awareness about Syringomyelia (SM). Because, it is through knowledge that answers are found. That will only happen if more people care.

### How You Can Help!

Educating your family, friends, and social media followers is a great way to teach others about SM, how it affects you (or someone you know) and how they can help make a difference!

If you're on social media, spread the word about Syringomyelia in just 3 easy steps:

- Follow us on Facebook, Twitter, Instagram, and YouTube. (Links available on ASAP.org)
- Like and share our education and research content.
- Use the materials from our website on your own social media accounts to help increase community awareness of SM.

Together, we increase public understanding and knowledge of this disorder!

Syringomyelia is a neurological disorder in which a fluid-filled cyst (syrinx) forms within the spinal cord. The syrinx can damage the spinal cord and compress and injure the nerve fibers that carry information to and from the brain to the body.

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  
**Chiari Friends**  
Chiari Cares  
**Ainsley Roark**  
Willetta Roark  
**Ann Schmidt**  
George & Elizabeth Zwierzynski  
**Cathy Ferry**  
Sam Ferry  
**Jaclyn Greenwood**  
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**Karen Dillard**  
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**Lisa Underhill**  
Michael Monroe  
**Patty Gary**  
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**Richard Simon**  
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**Wendi Manning**  
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Berger Family Foundation  
**Vince Mocini**  
**Dan & Nancy Sutherland**  
**Bill & Juliette Percy**  
**Eric Sutherland**  
**Annie Sutherland, MD**  
**John Sutherland**  
Timothy & Barbara Sutherland

#### In Memory of Donor

**Mickey Simon**  
**Ilene & William Ralph**  
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Beth Moore  
Carolyn Jensen  
Carolyn Watkins  
Chris & Laurie Goree  
Curtis Goedecke  
Janis Eldredge & family  
Kathaleen Wall  
Kathryn Schroeder  
Kelly Eldredge  
Kurt Goedecke  
Leigh Matthews  
Linda Schaefer  
Louise Palerno  
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Shawn Glanville  
Sonya Aston  
Timothy Tognetty  
Tomball Classes for  
Homeschoolers  
Yael Lavender-Smith  
Terry & Peggy Stockton

### 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](mailto:info@ASAP.org)

Patrice Schaublin,

Executive Director

[Patrice\\_Schaublin@ASAP.org](mailto:Patrice_Schaublin@ASAP.org)

Phone: 585-747-9651

Jamie Mayhan,

Programs Director

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

Patricia Maxwell,

Operations Director

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

### Discounted Room Rates Available at the Westgate Hotel

#### San Diego

July 24 – July 31

ASAP is celebrating 35 years with a \$35 gift  
off hotel rooms during July 26 – 28.

Voucher will be applied at check-in.

Register online: [https://www.ASAP.org/  
conferences/2023-conference](https://www.ASAP.org/conferences/2023-conference)





## Cormac O Maher Joins Stanford Department of Neurosurgery



Cormac O Maher, MD, serves on the ASAP Medical Advisory Board and hosted the ASAP annual conference in 2015 in Ann Arbor, Michigan. He been named pediatric neurosurgery division chief at Stanford Department of Neurosurgery as of March 1, 2023.

Dr Maher's areas of clinical interest include the surgical treatment of Chiari Malformation, arteriovenous malformations, Moyamoya disease, cavernous malformations, pediatric brain tumors, spinal dysraphism, tethered spinal cord, and hydrocephalus.

"I'm delighted that Cormac Maher has joined the department," said Michael Lim, MD, chair of neurosurgery. "Dr Maher is an internationally recognized surgeon with extensive experience in treating children and adults with congenital anomalies such as Chiari Malformation, brain tumors, vascular diseases, and tethered spinal cord. I look forward to seeing our pediatric neurosurgery division thrive under his leadership."

Dr Maher attended medical school at Georgetown University. He completed a surgical internship and neurosurgical residency at the Mayo Clinic in Rochester, Minnesota. After residency, he completed a pediatric neurosurgery fellowship at Boston Children's Hospital under the direction of R Michael Scott, MD. Afterward, he completed a fellowship in cerebrovascular neurosurgery at the Brigham & Women's Hospital. In 2006, Dr Maher joined the faculty of the University of Michigan where he served as professor of neurosurgery, Residency Program Director, and department Vice-Chair for Education.

Dr Maher has published over 200 articles on a wide variety of neurosurgical topics in scientific journals and medical books. He has made over 230 presentations of his work at national medical meetings. He has served on the editorial board of the Journal of Neurosurgery Publishing Group including a term as co-chair of the editorial board for Journal of Neurosurgery: Pediatrics. He has served as Chair of the Accreditation Council for Pediatric Neurosurgery Fellowships and is a director of the Committee for Advanced Subspecialty Accreditation of the Society for Neurological Surgeons. He is on the executive board of the Pediatric Section of the American Association of Neurological Surgeons.

"Dr Maher is an accomplished clinician-investigator," said Dr Lim. "He is uniquely qualified to further elevate our outstanding pediatric neurosurgery program."

## 10 Reasons to Attend ASAP's 35th Annual Conference

- 1. See presentations from 20+ top specialists.**  
Chiari and Syringomyelia patients often battle multiple disorders and comorbidities. Presentations will also cover related disorders including cranial cervical instability, mast cell syndrome, tethered cord syndrome, connective tissues disorders and more.
- 2. Hear world renowned doctors share strategies.**  
From "The Librarian Who Couldn't Wink" to medical marijuana, the hot topics covered in the 2023 conference are sure to spark your curiosity.
- 3. Exchange coping strategies.**  
Every journey comes with its own learning and understanding. Engage with your peers "during cocktail hours, dinner, social outings and downtime. Family members and caregivers are always encouraged to attend.
- 4. Get inspired to face your challenge head-on.**  
Take the next step in your healing journey. Meet those who donate countless hours of their time to promote awareness for Chiari and Syringomyelia.
- 5. Meet face-to-face with others.**  
ASAP connects thousands of members and subscribers to online and local support groups. The annual conference offers a rare opportunity to interact with like-minded friends.
- 6. Learn about the latest research.**  
The ASAP annual conference is a host of world-renowned surgeons and top experts. Conference speakers are engaged with cutting edge research and decades of experience.
- 7. Interact with doctors in social settings.**  
ASAP conferences offer several opportunities to interact with experts in a casual setting.
- 8. Have your burning questions answered.**  
Question-and-answer sessions with top neurology doctors is a can't miss opportunity.
- 9. Enjoy good food and discounted hotel rooms.**  
The Westgate Hotel includes fantastic amenities with an unbeatable reduced room rate for ASAP conference attendees.
- 10. Embark on a private tour of the San Diego Zoo!**  
As an added bonus, enjoy a zoo excursion with every registration ticket.

The American Syringomyelia & Chiari Alliance Project is proud to celebrate 35 years of providing education and support.



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**

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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.

Mail: ASAP Connections  
PO Box 1586  
Longview, TX 75606

Editor: Patricia Maxwell  
Email: [Patricia\\_Maxwell@ASAP.org](mailto:Patricia_Maxwell@ASAP.org)