

# ASAP CONNECTIONS

*Providing Research, Education and Support since 1988*



## ASAP Chiari & Syringomyelia Conference

**Sofitel San Francisco Bay**

**July 21-24 San Francisco Bay**

This annual event draws the top specialists in the field who bring years of experience to those who attend. During the four-day conference, everyone will gain knowledge of symptoms, treatments

and research. We will experience a unique opportunity, empowering us to improve our quality of life, make educated decisions about our medical care and help us take control. But one of the most rewarding benefits will be meeting and sharing this experience with others who personally know what it is like to live with Chiari and syringomyelia.

In keeping with this year's theme, speakers will be reflecting on what they were taught in the early years of their practice, how information has developed over time and how continued research will help future generations.

**Conference starts on Thursday this year!**

### Hotel Reservations:

- Conference Hotel:  
Sofitel San Francisco Bay  
223 Twin Dolphin Drive  
Redwood City, CA
- Call: 650-598-9000 – Request ‘in-house reservations’ and tell them you are attending the ASAP conference.
- Room Rate: \$155.00
- Cut-off Date: July 6

### Conference Registration:

- Register online at [www.ASAP.org](http://www.ASAP.org), click on ‘**Great Expectations**’ then ‘**Annual Conference**’ in side menu.
- Or complete the form inserted with this newsletter and return with payment to:  
ASAP  
PO Box 1586  
Longview TX 75606-1586

## A Sneak Peek

Speakers and topics for the ASAP conference:

- **Dr Brian Dlouhy, University of Iowa:** Craniocervical Junction
- **Dr Arnold Menezes, University of Iowa:** Complex Chiari Surgery
- **Dr Jeffrey Lazarus, UCLA:** Medical Hypnosis for Headaches
- **Dr Ulrich Batzdorf, UCLA:** Primary Syringomyelia (waiting confirmation)
- **Dr Harold Rekate, Chiari Institute:** Connective Tissue Disorders and Complex Chiari Malformations
- **Dr Paolo Bolognese, Chiari Neurosurgical Center at NSPC:** Complex Posterior Fossa Revisions
- **Dr Ian Carroll, Stanford:** Orthostatic Hypotension and Chiari
- **Dr John Heiss, NIH:** Syringomyelia
- **Dr Timothy George, Dell Children’s:** New Innovations in Chiari Surgery
- **Dr Bermans Iskandar, Univ of Wisconsin/Madison:** Chiari Surgery Failures, Point
- **Dr Robert Keating, CNMC:** Chiari Surgery Failures, Counterpoint
- **Dr Dave Limbrick, Washington University:** Park Reeves Foundation and Post Fossa Decompression Trial Update
- **Dr Tina Loven, Stanford:** Congenital Chiari Malformation Subtypes
- **Dr David Hong, Stanford:** Syringomyelia Pediatric Etiology
- **Dr Anand Veeravagu, Stanford:** Adult Syringomyelia Etiology
- **Dr Line Jacques, UCSF:** Syringomyelia Surgery Failures
- **Dr Brenda Golianu, Stanford:** Integrative Medicine, Pain Management (waiting confirmation)
- **Dr Roger Kula, Chiari Institute:** Chiari and Pregnancy and Chiari/Pseudotumor (waiting confirmation)

### Breakout Groups:

1. Nicole Hodgeboom PNP, Stanford: Pediatric neurosurgery, Palliative Pain
2. Anh-Thu Nguyen Lewis, CPNP: Pediatric Pain Management
3. Nancy Block: EDS Silicon Valley Support Group

A child life specialist from Stanford Children’s Health will be working with the KIDS For A Cure Club. Activities will include relaxation, dance and pet therapy.

## Stamp Project



ASAP members and friends have been collecting postage stamps as a fundraiser since the early 90's. 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



## Welcome New Director to ASAP Board



The ASAP Board of Directors elected to accept Dr Paolo Bolognese's application in March 2016.

A native of Torino, Italy, Paolo A Bolognese, MD, graduated magna cum laude in 1986 from the Medical School of the University of Turin. In 1990, he completed his neurosurgical

training at the same university under the guidance of Professor Victor A Fasano, an international leader in the field of high-tech applied to neurosurgery.

During this time, Dr Bolognese became the leading worldwide expert in the field of laser Doppler flowmetry applied to neurosurgery and the top European figure in the field of neurosurgical intraoperative ultrasound.

In 1992 he accepted the invitation of Dr Thomas H Milhorat to transfer his laser Doppler research to the United States. He retrained at SUNY Health Science Center at Brooklyn under Dr Milhorat where he completed his residency in neurosurgery, his fellowship in management of Chiari malformation and related disorders, and served as chief resident in neurosurgery.

In August 2001, Dr Bolognese joined Dr Milhorat at the Department of Neurosurgery at North Shore University Hospital and Long Island Jewish Medical Center as an Associate Director of the Chiari Center.

Along with Dr Milhorat, he co-founded The Chiari Institute, where he served as Associate Director until August 2014.

In September 2014, he joined Neurological Surgery, PC, as the Director of The Chiari Neurosurgical Center at NSPC. A frequent speaker at the ASAP Chiari and Syringomyelia Conference, Dr Bolognese has been an avid supporter of the Chiari and syringomyelia community for many years.

## Register Now!

**ASAP**

**Chiari & Syringomyelia  
Conference**

**San Francisco, CA**

**July 21-24, 2016**

**[www.ASAP.org](http://www.ASAP.org)**

**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.

Order Pet Food at  
**chewy.com** and they'll  
donate **\$20** to our cause!



[www.chewy.com/rp-resources/3654](http://www.chewy.com/rp-resources/3654)

## A Word From Our President



Do you want to make a difference? Do you want to enhance your professional development? Do you want to broaden your network? Do you want to have fun? Then ASAP wants YOU!

We are always looking for new and different ways to better serve our community and to improve the lives of those affected by syringomyelia, Chiari and related disorders. The best way we can do that is to involve our community members, family and friends who share the same passion for helping others while we find the cure. The benefits to the community are obvious: support, research funding, education, awareness campaigns, etc., but what are the benefits to you?

Starting a support group, serving on the board, or by volunteering for a committee (i.e., marketing, technology, etc.), YOU can make a difference. No matter how large or small the time investment you make, you will enjoy the experience of helping others. The feeling of contributing to something larger than yourself and helping others is tremendously satisfying and uplifting.

You will enhance your professional development. There are many areas to become involved: awareness campaigns, fundraising events, budgets, etc. You can enhance existing skills or possibly try some new ones. The choice is yours. You will meet and connect with many new people through your new role. In this way, you will strengthen and broaden your existing network. Think about how that will be of benefit to you in your existing and future endeavors. Not to mention the many new friends you will make who share the same passion and common bond.

Your service on a committee, support group or the board of directors will require a certain time commitment, but where better to spend your time to reap such great rewards. A few hours a week is the most it would take, and both you and the CM/SM community will reap tremendous rewards. ASAP has succeeded because of its volunteers and we will continue to succeed with an investment of your time.

Won't you consider joining us? Our work is so important. In order to continue to provide the community with top notch services and programs we would like you to consider volunteering. Please take a moment and express your interest by clicking on the link below. You can also contact us at 903-236-7079. Do it today! You will be happy you did.

<http://ASAP.org/index.php/volunteer/>

Gentle Hugs always,  
Patrice  
Patrice\_Schaublin@ASAP.org

## How to Prevent Addiction

Some medications used to treat pain can be addictive. Addiction is different from physical dependence or tolerance, however. In cases of physical dependence, withdrawal symptoms occur when a substance suddenly is stopped. Tolerance occurs when the initial dose of a substance loses its effectiveness over time. Addiction is a psychological and behavioral response that develops in some people with the use of narcotic pain medicines.

People who take a class of drugs called opioids for a long period of time may develop tolerance and even physical dependence. This does not mean, however, that a person is addicted. In general, addiction occurs in only a small percentage of people when narcotics are used under proper medical supervision.

The key to avoiding addiction is to take your medicine exactly as your doctor prescribes.

Share with your doctor any personal and/or family history of substance abuse or addiction. Your doctor needs this information to prescribe the medicines that will work best for you. Fears about addiction should not prevent you from using narcotics to effectively relieve your pain.

Remember, it is common for people to develop a tolerance to their pain medication and to need higher doses to achieve the same level of pain relief. Such a situation is normal and is not a sign of addiction. However, you should talk to your doctor if this effect becomes troubling.

## 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, Texas 75601

Phone: 903-236-7079

Fax: 903-757-7456

Toll-free: 800-ASAP-282

Email: [info@ASAP.org](mailto:info@ASAP.org)

Staff:

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

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

## Frequently Asked Questions About the Conference

### **When does the conference start?**

The conference begins on Thursday, July 21 at 6:30 pm with registration followed by a social hour. Attendees will pick up conference materials, enjoy light refreshments and meet other attendees.

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

Sofitel San Francisco Bay

223 Twin Dolphin Drive

Redwood City, CA 94065

650-598-9000

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

\$155 plus 12% tax per night and \$1.50 County Tourism Assessment. Reservations for the event will be made by individual attendees directly with Sofitel reservations at 650-598-9000. When making reservation let them know you are attending ASAP's Chiari & Syringomyelia Conference to receive this rate. If you have any problems, please let us know. Call 903-236-7079 or email info@ASAP.org

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

Rooms must be reserved on or before July 6, 2016 to receive the discounted rate. Only a limited number of rooms are available at this rate so make your reservation early if you know you are coming.

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

Staying at the Sofitel offers the convenience of being near the conference proceedings and benefits the organization. You will also have the opportunity to spend social time with other attendees.

### **What airport serves San Francisco Bay?**

San Francisco International Airport – SFO

This hotel provides free shuttle service to and from the San Francisco International Airport.

### **What is the registration fee for attending the conference?**

Pre-registration:

Adults 16 & up: \$160 each

Children ages 5 – 15: \$85

Family pack: two adults and two children: \$450

No charge for children under 5, over 15 years must register as an adult.

The registration fees include: all lectures and workshops, Wednesday night refreshments, breakfast Friday, Saturday and Sunday and Saturday evening banquet meal.

### **We do not want to attend the banquet, can we get a reduced rate?**

You can register using the day rate at \$60 per day. This will include the group breakfast.

### **Can I come for only one day?**

Yes. If you are not able to attend the entire conference, you can pay by the day.

The day rate is \$60. Registration fee includes the group breakfast which is served before sessions begin.

### **Can my family/friends who are not attending the conference come to the Saturday night banquet?**

Yes. You can purchase a 'banquet only' ticket for \$65.

### **When is the last day to register?**

You can register online, by phone, or through the mail until July 10. After that date, you may register on site but the cost per person is slightly higher: \$185.

### **Can I get a refund if something happens and I can't attend?**

Yes. Refunds will be given until June 30, minus a \$25 handling fee.

### **Can children attend the conference?**

Absolutely, we encourage you to think of the conference as a family event. We have special sessions for children and teens (5 – 16 years) with Chiari, syringomyelia or related disorders as well as siblings and children whose parents are affected. When one member of the family is diagnosed, it affects everyone! The conference allows patients, family and friends to interact and share with others who understand their unique perspectives.

### **Doesn't the conference usually start on Wednesday?**

In order to secure a more reasonable guest room rate for attendees, the meeting dates were shifted one day later this year. Plans are to return to the normal schedule next year.

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

The agenda is still in development at this writing. However plans are to end around noon on Sunday July 24. As soon as the agenda is completed it will be available on the website.

## **Steps to Being an Effective Self-Advocate, Part II**

In the last issue we talked about believing in you and how to raise self-esteem. Now that you are feeling better about yourself, it is time to decide what you want.

Think about your life. What is it that you need and want for yourself? Make a list of these things. If the list gets too long, don't worry. Later you can take a second look and decide which of these things could you achieve, or try to achieve, by advocating or speaking out for yourself. Of the items on your new list, what is most important to you? Rank them in order of importance.

Through this simple process you have identified your needs or goals and how important they are to you in your life. It would be a lot of work to tackle all of them at the same time. Start with your top priority. After you have met that goal, or are coming along well with it, you can start on the next one. Keep in mind that your needs may change from time to time. What seems like a high priority in the beginning may not seem like one in several months.

### **Get the facts.**

When you speak up for yourself, you need to know what you are talking about. You need to gather information and make sure the information you have is accurate. There are many ways to accomplish this:

- Ask people who have done something similar or who have been in a similar situation.
- Study books and other resources you can access through your library, related organizations and agencies, or the internet.
- Contact various agencies and organizations, especially those that specialize in advocacy and education and that serve people with disabilities.

If this is hard for you to do, ask someone you trust to help you. Write down the facts or make copies and keep them where you know you can find the information when you need it. Use your own common sense to decide whether a source of information should be believed. If you are unclear, ask someone with expertise in the area to help you decide if the information you have found is accurate.

### **Plan your strategy.**

Now it is time to decide what steps you need to achieve your goal. You may want to set a time line with even small goals to achieve by certain dates. Try to think of several ways to address the problem in case one way doesn't work out. Ask supporters for suggestions. Get feedback on your ideas. Then choose your strategy.

### **Gather support.**

It is easier and usually more effective to work on getting what you want and need for yourself if you have the support. Enlist the help of a friend, family member or health care provider. A good supporter is someone who:

- you like, respect, and trust, and who likes, respects, and trusts you;
- allows you the space to change, grow, make decisions, and even mistakes;
- listens to you and shares with you, both the good and the bad;
- respects your need for confidentiality so you can tell them anything;
- gives you good advice when you want and ask for it, assists you in taking action that will help you feel better, and works with you to figure out what to do next in difficult situations;
- doesn't ever take advantage of you.

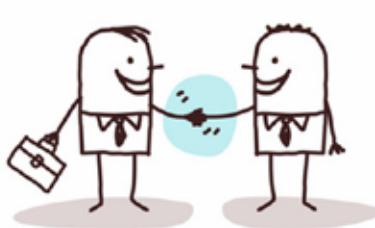
Tell your supporters you are working on becoming a better advocate for yourself. Ask them if they would be willing to help you in this effort by listening to you, giving you advice and feedback from time to time, and being with you when you are taking some difficult steps. However, don't overwhelm your supporters with your problems and needs. And be there for them when they need your help.

Keep in mind that even the very best friend may inadvertently let you down from time to time. No one is perfect. Try to forget the incident and continue with the good relationship you have.

### **Target your efforts.**

Find the right person or organization that can help you reach your goal. Make an appointment and ask for what you want. Be on time. Look the person in the eye. Shake hands firmly and call the person by name. First impressions are important and you want to make a great one. Keep your request brief and to the point. State your concern and how you want things changed. Be clear and simple.

Listen to the other person's response. If you don't understand, ask questions for clarification. If you feel you are not getting anywhere, tell the other person that you wish to pursue your issues further and ask to speak to the person's supervisor.



At the end of the meeting, restate any action that has been decided upon so you both understand each other clearly.

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

#### Austin Rodriguez

Teri's Run Foundation

#### Christine Grabowski

Plesantville School

#### Justin & Lynn Marotta

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### 1st Annual Kicks and Licks

Dr Lauren Talarico, DVM, DACVIM, hosted a walk, doggie fashion show and on-site exams (for dogs) on April 16 at Bluemont Park in Arlington, Virginia. Attended by both two and four legged participants, the event raised over \$13,000.



If you would like to plan a Kicks and Licks Walk in your neighborhood contact Patrice Schaublin at [Patrice\\_Schaublin@ASAP.org](mailto:Patrice_Schaublin@ASAP.org)

## **Preparing for Your Appointment with a New Doctor**

Since specialists have very busy schedules, preparing ahead of time will help things run more smoothly. You will also be less stressed and retain more information. Here are some ideas to help you get ready and know what to expect.

When making your appointment find out what you can or need to do in advance. Filling out new patient forms and providing copies of medical records can take time. So make sure the doctor has them well in advance of your appointment. You will also want to write down the symptoms you're experiencing. Keep a journal to help pinpoint when they occur and any activity preceding the onset. Make a list of all medication, over the counter medicines, vitamins and supplements you take. Make a list of your questions you have. If the doctor doesn't have time to answer them, ask him/her if they will take the list so they can answer them when they have the time.

Take a family member or friend with for the appointment. They will provide support for you and an extra set of ears. Sometime when receiving medical diagnosis we develop tunnel vision and become focused on a specific fact. Another person can offer a different opinion or perspective of what you hear.

Typical questions you might want to ask your doctor:

- What is likely causing my symptoms or condition?
- Are there other possible causes for my symptoms or condition?
- Is there a possibility my symptoms will get better on their own?
- What kinds of tests do I need?
- Is my condition likely temporary or chronic?
- Is my condition related to my diet or environment?
- What is the best course of action?
- What are the alternatives to the primary approach that you're suggesting?

- Can exercise help?
- I have other health conditions. How can I best manage them together?
- Are there any restrictions that I need to follow?
- Should I see a specialist?
- Are there any brochures or other printed material that I can take home with me? What websites do you recommend?

When making your list of questions, be sure to place them in the order of importance to you. Since you probably will not be able to ask all of them during the appointment, you want to be sure he has time to answer the most important ones during the visit.

Your doctor is likely to ask you a number of questions. Being ready to answer his questions may reserve more time for your own. Be as specific as you can when answering. Your doctor may ask:

- When did you first begin experiencing these symptoms?
- What is your pain level?
- Have your symptoms been continuous or occasional?
- How severe are your symptoms?
- What, if anything, seems to improve your symptoms?
- What, if anything, appears to worsen your symptoms?

While waiting for your appointment, try to avoid anything that seems to worsen your symptoms. Keeping a journal will help pinpoint some of these factors. Some known causes to watch out for are straining, lifting heavy objects and stress. As each individual is different, you may have other or different triggers.

Be better prepared for your next appointment. Remove some of the stress and help retain more information.

## **FDA Takes Step to Increase the Development of, and Access to, Abuse-Deterrent Opioids**

Agency issues draft guidance for abuse-deterrent generics  
March 24, 2016

The U.S. Food and Drug Administration issued a draft guidance intended to support industry in their development of generic versions of approved opioids with abuse-deterrent formulations (ADF) while ensuring that generic ADF opioids are no less abuse-deterrent than the brand-name drug. These actions are among a number of steps the agency recently outlined in an action plan to reassess its approach to opioid medications. The plan is focused on policies aimed at reversing the epidemic, while still providing patients in pain access to effective relief.

The draft guidance issued in March (titled “General Principles for Evaluating the Abuse Deterrence of Generic Solid Oral Opioid Drug Products”) includes recommendations about

the studies that should be conducted to demonstrate that a generic opioid is no less abuse-deterrent than the brand name product, with respect to all potential routes of abuse. Today’s draft guidance for generic abuse-deterrent opioids follows the agency’s final guidance for brand name opioids, “Abuse-Deterrent Opioids - Evaluation and Labeling,” which was issued April 2015 as the first step to provide a framework for what studies were needed to test a product’s ability to deter abuse.

To download a pdf of the “Draft Guidance for Industry: General Principles for Evaluating the Abuse Deterrence of Generic Solid Oral Opioid Drugs Products: go to: <https://www.federalregister.gov/articles/2016/03/25/2016-06766/draft-guidance-for-industry-general-principles-for-evaluating-the-abuse-deterrence-of-generic-solid>

American Syringomyelia & Chiari Alliance Project Inc.  
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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.

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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



## ASAP's Chiari & Syringomyelia Conference

July 21-24, 2016

### Attendee Registration Form

Pre-conference registration closes July 10

Attendees may register at conference for a slightly higher fee.

#### Contact Information

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

#### Additional Attendees

Please add contact information if different from above. List each child's age after their name..

Name: \_\_\_\_\_

Name: \_\_\_\_\_

List additional attendees and contact information if needed on back.

Fees	Number	Sub-total
Adult registration by July 10 (includes breakfasts & banquet):	_____ x \$160.00	_____
Children's registration: ages 6 - 15 (includes breakfasts & banquet):	_____ x \$ 85.00	_____
Additional banquet tickets:	_____ x \$ 65.00	_____
Family pack: 2 adults, 2 children (ages 6-15)	_____ x \$450.00	_____

Includes banquet (Saturday) & breakfast ( Friday, Saturday and Sunday)

Number of vegetarian entrees banquet: \_\_\_\_\_

Special diet request: \_\_\_\_\_

**Note:** By submitting this form and/or attending the conference, you agree to allow ASAP to use photographs and/or videos taken of you in ASAP's promotional materials. You understand that ASAP will not publish or record any personally identifiable information without your express written consent.

#### Payment Information

I want to make a donation. Scholarship Fund \$ \_\_\_\_\_ Conference Sponsor \$ \_\_\_\_\_

Payment Type:  Check  Credit Card Total Amount Enclosed (see sub-total above): \$ \_\_\_\_\_

Credit Card Type:  Visa  MasterCard  Discover  American Express

Cardholder Name (please print): \_\_\_\_\_

Credit Card Number: \_\_\_\_\_ Expiration Date: \_\_\_\_\_

Cardholder Signature: \_\_\_\_\_

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ASAP Conference Registration  
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