

# ASAP CONNECTIONS

*Providing Research, Education and Support since 1988*

## Cell Therapy Trial for Paralysis Gets FDA OK

The Miami Project to Cure Paralysis received permission from the FDA to begin a Phase I clinical trial to evaluate the safety of transplanting human Schwann cells to treat patients with recent spinal cord injuries (SCIs).

Found mainly in the peripheral nervous system, Schwann cells are essential to sending appropriate electrical signals through the nervous system, and Miami Project scientists and supporters believe they are key to finding cures for paralysis. In what will reportedly be the only FDA-approved cell therapy-based clinical trial for sub-acute spinal cord injury in the U.S., investigators plan to transplant a patient's own Schwann cells at the injury site in the hope of ascertaining safety that will allow further trials to proceed.

The clinical trial will enroll eight participants with an acute thoracic SCI. Newly injured patients brought to the trauma center would have to meet the stringent criteria and agree to participate in further screening within five days of their injury. At that point, the participant will undergo a biopsy of a sensory nerve in one leg to obtain his or her own Schwann cells. The Schwann cells will then be grown in a culturing facility for three to five weeks to generate the number of cells necessary for transplantation, and to undergo the strict purification process. By the time the Schwann cells are surgically transplanted into the injury site, participants will be 26–40 days post-injury.

All procedures will be conducted in Miami at University of Miami Hospital, Jackson Memorial Hospital, and The Miami Project to Cure Paralysis. Each participant will be followed intensely for one year after receiving the transplantation surgery, and their neurologic status, medical status, pain symptoms, and muscle spasticity will be evaluated. All participants will continue to be monitored for years under a separate clinical protocol. This Phase I trial is the foundation upon which The Miami Project will develop future trials targeting different types of injuries, times post-injury, and therapeutic combinations.

The Miami Project is a comprehensive spinal cord injury research center and a designated Center of Excellence at the University of Miami Miller School of Medicine. The project's Christine E. Lynn Clinical Trials Initiative takes discoveries found to be successful in laboratory studies and fast-tracks them to human studies.

## ASAP Member Helps Others Walk

Kevin Jacobs doesn't have to walk very far to get to work. Tucked away in a corner of his family room is his little workshop complete with all the tools he needs to make one-of-a-kind walking canes.

Over twenty years ago he was involved in an accident and developed syringomyelia. In 2008, after retirement, he started making canes out of wood. The canes are made with either Russian Olive, snowball bush, ash or diamond willow; whatever Jacobs can get his hands on. All the work to create these unique canes is done by hand.

"I don't want any machinery touching my work," he said. "I want the satisfaction of doing it all by hand."



Just making the unique "T" handle has seven steps involved, which Jacobs won't divulge. Twigs, matchsticks or toothpicks seal the seams.

"It takes me a couple of days to whittle the wood and from one to two days to complete the cane," Jacobs said. "A redwood stain with a couple coats of varnish completes the job."

Jacobs has donated his canes to the Basin Retirement Home, VA hospitals in Sheridan, Buffalo and Cheyenne, and the Pioneer Nursing Home. Every year he donates several to ASAP for fundraising events.

## Stamp Project

We sincerely appreciate everyone's contributions to this project. Please send stamps that are in good condition (attached to envelope and trimmed with 1/2 inch border around undamaged stamp) to the ASAP office. We are looking for a volunteer to spearhead the stamp project. Interested persons should contact the ASAP office.



ASAP Stamp Project  
300 N Green St Ste 412  
Longview TX 75601

## SPREAD AWARENESS with an ASAP Business Card

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

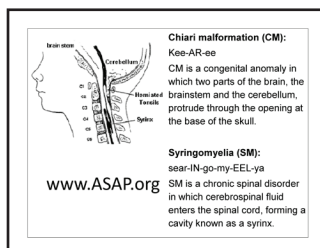
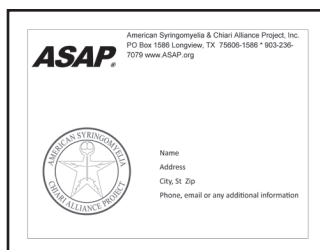
Order personalized ASAP business cards with a brief description of Chiari and syringomyelia on the back.

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

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

Mail to: ASAP  
PO Box 1586  
Longview TX 75606

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



**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.

## Special Thanks ASAP 2012 Awards

**Helping Hand Award** - These volunteers keep ASAP running smoothly! By giving their time, energy and/or talents, they help us to further our mission. Recipients are:

**Tamra Allgood - Tammy Brown - Peg Curtacci Mandy Dowling - Blair Hagelgans  
Mandy Hammes - Tammy Helms  
Agata Piraino - Cathy Piraino - Leslie Schrader Laura Sottile - Ann Taylor - Anna Tannreuther Shawn Tringham - Mary Young  
Celeste Wilson Ramseur**

**Visionary Award** - Volunteers who are committed to furthering the goals of ASAP by donating their time and talents to keep ASAP moving forward. Recipients are:

**Marc Davis - Heidi Jagoe - Joe Levinson  
Michael Salasky - Eva Storey - Laurie Yeh**

**Shining Star Award** - Volunteers whose continuous efforts go above and beyond. They are a shining example of volunteering at its best! Recipients are:

**Shananne Hutter - Maureen Routledge  
Laurie Swilhart - Cathy Tufts**

**Key Volunteer Award** - In recognition of exceptional service and contributions, these volunteers play a vital role in helping ASAP open new doors! Recipients are:

**Wendy Skoch Hart  
Candida Lancaster**

**Barbara White Award** - ASAP's most prestigious award is given in recognition of outstanding contributions to further the efforts of our co-founder, Barbara White. Recipient is:

**Judy Hunt**

**Outgoing Board Members** - The Board of Directors is the final authority on operation of the American Syringomyelia & Chiari Alliance Project, Inc. ("ASAP"). It has complete responsibility for the control and management of the affairs, funds and property of ASAP including, but not limited to, final approval of the budget and other fiscal matters, approval of all policies, and delegation of policy implementation. Recipients are:

**Judy Hunt 1997 - 2011  
Matt Turmelle 2010 - 2011  
Barbara Banick 2010 - 2012**

## A Word From Our President



I am thinking about this letter and my thoughts are in so many directions since the conference but I know where I would like to begin. I would like to thank everyone for a successful event, our host Robert Keating MD, the conference committee, those who donated auction items, those who helped

at the conference itself and most importantly the speakers who donated their time to ASAP. Without your cooperation in working as a team and all your hard work, it would not have been possible. So with deep and heartfelt regards, I thank you.

At conference after speaking to many people, I came to the realization that we have come a long way but we still have an uphill journey. Yes, we do research. We all know research is very important but meeting the needs of our members in the CM and SM community goes beyond research.

Many of us don't think of a trip to the supermarket is anything special, but for many of us it is. Not a day goes by that many of us don't live in chronic pain and our families are lost as to what to do. This is why ASAP holds so strongly to its mission which is *to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure*. We are helping others to have hope and build confidence that we can build a better tomorrow.

I speak to many people; the interesting thing is that much of the conversation is the same. I've heard, *We have trouble with the school system understanding our child's illness. Many doctors misdiagnosed me. I have lost many friends and family members who don't understand that I don't feel well because I look fine. I've never met anyone with CM/SM until I came here.* I was also told by many that *it feels so good not to feel ALONE anymore. I have learned so much from the speakers and from sharing our stories. I feel like ASAP is a big family. The organization has done so much for us.* With all that being said, ASAP is here for you and your families. We take great care in providing you with the help you need. Knowledge and support are key to your well-being.

We all reach a time where support and encouragement of a community is invaluable. We need encouragement to try harder, push forward, take a deep breath and hold on, blink our eyes and try to take a new look. I know that is not easy. These words come from someone who is in the same position as you. I ride that same merry go round, even though I look ok. I have children also with the disorders however I am lucky enough to have a supportive family and I try every day to make my day better by seeing my glass as half full, and by trying to help others in our community. The more positive we can be, the better we will feel. I don't know how many times a doctor told me that stress is a factor and the more you feed into what you can't do instead of what you can do, it will have an effect on you.

I am asking you, our members and families, to help support us in the continuing growth of ASAP. We provide support, education, research and much needed awareness. ASAP is here for all of you, but we need your help also.

We offer our community webinars, a national conference, children's program, support groups, message board, educational materials and so much more. We have many committees and programs through which you could be involved. Providing all of this requires more than a handful of individuals. I am opening the doors to you, our members, once again to be involved in ASAP's future. Each committee has only one meeting a month held on a teleconference call. If we all work as a team, think of how much more we could do! Do you have a few hours a month to spare? Your opinions are always appreciated.

Most of our staff is made up of volunteers. We have only two paid employees. The volunteers give anywhere from 7 days a week, to a few hours a week but staff or volunteers alone do not keep ASAP operational. In order to meet our obligations your financial support is also needed. We are grateful for your donation regardless of the amount. I am urging everyone in our community to seriously consider ASAP when planning your 2012/2013 charitable donations. Any amount you can contribute would be most welcomed and appreciated.

We have many things planned this year. We are celebrating our 25th Anniversary. We have made progress in the 19 years that I have been involved with ASAP but as encouraging as the progress is, worlds of work still need to be done. Simply stated, we need your help to move forward. Quality in an organization depends, to a great extent, on what they have to offer. We have many things to offer you including a new program. Through The L.E.A.R.N. Program, it is now possible for anyone to attend our national conference.

So, as we move forward, we need your help. We need to continue our support to help those families being diagnosed and guide those families who are living with these disorders. We need to continue our awareness in the medical community and ultimately we need *to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure*.

I would like to thank you for your help and support. I look forward to working with you and continuing to serve you.

Sincerely Yours,  
Gentle Hugs,

Patrice

ASAP BOD President  
Patrice\_Schaublin@ASAP.org



## ASAP's Chiari & Syringomyelia Conference

Attendees share their experiences: due to limited space we have only included a sampling in the newsletter. Go to ASAP.org to read them all.

I was surgically diagnosed with a syrinx in 1975 and, later, with a hindbrain herniation. I've done miraculously well for 30+ years but am now experiencing an accelerating progression of symptoms. Surgery is likely on the agenda and I need to become more fully educated before I am able to discuss this intelligently with my surgeon and, ultimately, to make decisions that are appropriate for me. The Arlington conference moved me ahead in this process quickly and sensitively. - Al P, Massachusetts

Thank you ASAP for putting together such a phenomenal conference. Every single presentation was so beneficial and to have the top experts in the country there presenting was truly an amazing experience. - Cathy T, Texas

The conference in Washington D.C. was our first conference to attend. We feel like we now have the information we need to make informed decisions in the future. - Tommy and Sandy T, Texas

I truly loved meeting other people who share in the same struggles as my family. - Becky L, New York

My family and I were able to attend the 2012 ASAP Conference through the L.E.A.R.N program this year. We learned that there are benefits from things like acupuncture, how fibromyalgia is related and treatments, and about the psychological factors of chronic pain. My children loved meeting new friends in the children's program and had so much fun with Mary and Annie. - Lori T, Indiana

The ASAP Conference had the BEST list of professionals in our field imaginable. Dr Batzdorf was the highlight of my visit with his amazing history information of SM. Personally the most interesting lecture for me was Bryn Martin, PhD, the engineer working on neurohydrodynamics. - Madeline L, New York

The ASAP conferences are so much more than priceless medical information. You meet people that "get it" and that changes your life in such an amazing way. - Sarah R, Indiana

Attending the 2012 ASAP Conference strengthened my understanding of Chiari and syringomyelia empowering me when strategizing with my sons' physicians. The embryologist and geneticist back to back and the cine discussion followed by the 3-D MRI highlight the complexities of these challenges. I appreciated Dr. Gesina Keating's How To Get A Good Diagnosis lecture and Keith Bell's discussion on complimentary care. - Susie H, Virginia

Being on the conference committee for the first time this year, I experienced first-hand how much time and effort goes into planning this conference. This year the highlight for me was the breadth of speakers Dr. Keating was able to secure. From neurosurgeons to psychologists to a Chinese medicine expert, we heard from them all. It was such a wonderful event I was blessed to be a part of! - Kerry C, Texas

I had often heard the expression that "knowledge is power." That statement certainly proved to be so true during the recent ASAP conference. I learned how important it was for patients to focus on only what they can do by using 5 cognitive coping strategies. - Yvette D, DC

I learned so much! But I think what stands out in my mind the most is that I'm not alone! Hearing others described what they are going through, and relating to it helped to validate what I'm going through. Also having the doctors speak to us like we are real people with real problems (and not being shrugged off) was encouraging. I can't wait for next year! - Sharon S, New Jersey

Most uplifting conference I've ever attended. Put life's real challenges in perspective and answered me and my family's long time quest about why was I so different. - Helen S, Virginia

I learned to listen to my body a little more, and that I'm not alone. - Celina P, Maine

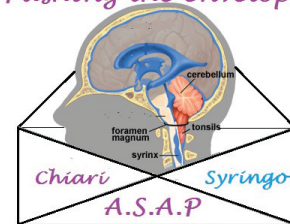
A wealth of useful information coupled with encouragement and hope, motivated us to push forward for better solutions. - BJ and Jenn D, Georgia

I was fortunate to have attended the 2012 ASAP conference in Arlington, VA (my fourth conference). I was especially impressed with the scientific program, and to the dedicated doctors and researchers. - Jeanne S., Wisconsin

I took away more information than I ever knew about ASAP. Being with other people that have Chiari, was more than I expected, I got information from them and they helped me better understand more about what my granddaughter is going through and will go through in the future. God Bless you all. - Sandra H, Virginia

[Stay tuned for updates on location and conference host for 2013. We look forward to celebrating our 25th Anniversary with you next summer.]

*Pushing the envelope*



*While we find the cure!*

## Medication Assistance Resources

If you cannot find a patient assistance program for your medication, try contacting the manufacturer of the drug for possible program opportunities or financial assistance. This information should be available through your physician's office or pharmacy.

**NORD's Patient Assistance Programs** help patients obtain life-saving or life-sustaining medication they could not otherwise afford. <http://www.rarediseases.org/patients-and-families/patient-assistance> or call 203-744-0100 or 800-999-NORD (tollfree)

**RxAssist** offers a comprehensive database of patient assistance programs, as well as practical tools, news, and articles so that health care professionals and patients can find the information they need. Patient assistance programs are run by pharmaceutical companies to provide free medications to people who cannot afford to buy their medicine. <http://www.rxassist.org/default.cfm> (online resource only)

**Care Connect USA** has assembled a free list of family relief hotlines for financial assistance in critical categories. Some of these hotlines are government agencies, and some are privately administered. All have met their standards of practice, and are monitored for continued effectiveness.

- Mortgage Payment Assistance- 800-750-8956
- Debt Relief Hotline- 800-291-1042
- Discount Prescription- 800-291-1206

**Healing the Children** works to heal children with burn injuries, cleft palates and other deformities whose families don't have access to or cannot afford treatment. <http://www.htcne.org> or call 860-355-1828 or 860-350-6634

**The HealthWell Foundation** is a 501(c)(3) non-profit organization established in 2003 that is committed to addressing the needs of individuals with insurance who cannot afford their copayments, coinsurance, and premiums for important medical treatments. <http://www.healthwellfoundation.org/> or call 800-675-8416

**Hill-Burton Free and Reduced Cost Health Care** provides a reasonable volume of services to persons unable to pay

for hospitals, nursing homes and other health facilities, and to make their services available to all persons residing in the facility's area. <http://www.hrsa.gov/gethealthcare/affordable/hillburton/> or call 800-638-0742



**Medicationfoundation.com** provides links to online pharmacies, medications, prescription discounts and other resources.

**SelectCare Benefits Network** is a patient assistance program to help you receive each of your medications for as little as \$25 per month. <http://www.myrxadvocate.com> or call 877-331-0362

**SCBN** is a patient assistance program to help you receive each of your medications for as little as \$25 per month. <http://www.scbn.org/> or call 888-331-1002

**The National Human Genome Research Institute** provides some resources for finding information on financial aid for medical treatment, although it is not authorized to provide routine medical assistance or treatment funds. <http://www.genome.gov/11008842#insurance> or call 202-619-0257 or 877-696-6775 (toll free)

**The Patient Advocate Foundation (PAF) Co-Pay Relief Program** (CPR) currently provides direct financial support to insured patients, including Medicare Part D beneficiaries, who must financially and medically qualify to access pharmaceutical co-payment assistance. <http://www.copays.org/> or call 866-512-3861

**Patient Services, Inc. (PSI)** provides peace of mind to patients living with specific chronic illnesses by: locating health insurance in all 50 states, subsidizing the cost of health insurance premiums, providing pharmacy and treatment co-payment assistance, assisting with Medicare Part D Co-insurance, and helping with advocacy for Social Security Disability. <https://www.patientservicesinc.org/> or call 800-366-7741

## 2012 ASAP Chiari & Syringomyelia Conference Speakers

A very special thank you to these speakers who donated their time and expense to educate others.

Allison Ashley-Koch, PhD  
Robert Avery, DO  
Ulrich Batzdorf, MD  
Keith Bell  
Ann Berger, MSN, MD  
Laurel Blakemore, MD  
Paolo Bolognese, MD  
Marc Disabella, DO

Timothy George, MD  
Gerald Grant, MD  
Tanya Harvey  
John D Heiss, MD  
Bermans Iskandar, MD  
Gesina Keating, MD  
Robert Keating, MD  
Roger W Kula, MD

Lance LaCerate, PSY D  
David Limbrick, MD  
Suresh Magge, MD  
Bryn Martin, PhD  
Arnold Menezes, MD  
John Myseros, MD  
Jerry Oakes, MD  
John Oró, MD

Chase Phillips  
David Pincus, MD  
Mark Quigley, PhD  
Jeffrey Rabin, DO  
Harold Rekate, MD  
Kerri Thorn, PA-C, MPH, ISHS

Remember ASAP...

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

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

#### **In Honor of**

##### *Donor*

Lauren Burton's Bat Mitzvah

*Heidi Slurzberg*

Danny Clemenson

*Star Sharing Time &  
Resources*

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*Robert & Mary LaPlante  
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*Cecila Fitzpatrick*

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*Darryl Culver*

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*Glen & Melissa Lussier*

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Guy & Marlene Petersen's

60th Anniversary

*Guy & Marlene Petersen*

Jacqueline Babitts

*Steven & Rosa Babitts*

Sara Santiago

*Xiomara Santiago*

Charles & Fay Christianson

*Guy & Marlene Petersen*

Maverik Schrock

*Carolina Courts Fundraiser*

#### **In Memory of**

##### *Donor*

Gina Swart

*Jerry Swartz*

Maynard Guss

*Flora Guss*

Cookie Friez

*Jim, Becky Sprunger &  
family*

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Seigbert Oppenheimer

*Margot Oppenheimer*

Mylee Grace Eaton

*Kathleen Hall*

*Shelley Norris*

Guy Rowe

*Guy & Marlene Petersen*

Anna Kula

*Patrice Schaublin*

Douglas Gober II

*Patrice Schaublin*

Robert Hettermann

*Ann Schmidt*

Patti Nelson

*Ann Schmidt*



**Honor a loved one with a gift to ASAP on special occasions or just to let them know you care. For donation of \$5 or more, ASAP will send an acknowledgement card to the individual.**

**Remember family and friends with a memorial gift to ASAP. Acknowledgement cards will be sent to family when an address is provided.**

## **ASAP History**



The American Syringomyelia Alliance Project, Inc. (ASAP) is a not-for-profit, 501(c)(3) member supported organization chartered in May 1988. ASAP is the result of the commitment and determination of its two founding members, Barbara and Don White, whose journey with syringomyelia began in 1983, in Longview, Texas.

Barbara was experiencing numbness in her left hand, headaches and other unexplained symptoms. After three weeks of hospitalization and testing, she was finally diagnosed with syringomyelia (SM). Their efforts to learn about the condition proved to them that very little was known about SM, and few physicians were even aware of the limited information that was available. Finding a physician who had treated more than a handful of patients was almost impossible. The frustrations they faced years ago mirror those of many SM patients even today. One of their goals in forming ASAP was to provide others with support and direction facing SM. Unfortunately, Barbara White did not live to see the blossoming of her organization. She died from complications of SM in 1991. However, ASAP continues to make strides toward the goals she and Don set.

## **Contact Information**

### **American Syringomyelia & Chiari Alliance Project**

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

Phone: 903-236-7079

Fax: 903-757-7456

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

Staff: Patricia Maxwell & Jamie Mayhan

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

## ASAP CHAPTER LEADERS NEEDED

Our ASAP Chapters continue to grow providing support group meetings throughout the country. However, we still need **your help!** If you do not see a support group near you on the list below and are interesting in starting one in your area, please contact Kerry Chu at [kerry\\_chu@asap.org](mailto:kerry_chu@asap.org) or call 903-236-7079.

Please keep your eyes open for emails from ASAP with upcoming meeting information about the following active groups:

- AZ Syringo & Chiari Support Group – Phoenix, AZ
- ASAP's Eastern Iowa Chiari/Syringo Support Group – Cedar Rapids, IA
- ASAP's Indy Chiari/Syringo Support Group – Greenfield, IN
- ASAP's Tampa Support Group – Tampa, FL
- Midwest ASAP Connection – Blaine, MN
- Durham, NC Support Group – Durham, NC
- ASAP's Long Island Support Group – Garden City, NY
- North Jersey Arnold Chiari & Syringomyelia Alliance – Boonton, NJ
- Southern, NJ – New group in forming stages
- ASAP's Butler, PA Chiarians – Butler, PA
- Chiari People of PA – Mohnton, PA
- ASAP's Charleston Area Chiari/Syringo Support Group – Charleston, SC
- ASAP's Central Houston Chiari/Syringo Support Group – Houston, TX
- ASAP's North Houston Chiari/Syringo Support Group – Cypress, TX
- Blacksburg, VA – New group in forming stages
- Edmonds, WA Support Group – Edmonds, WA
- ASAP's Madison, WI Chiari/Syringo Support Group – Madison, WI

## Welcome To Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."



"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.



It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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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 bimonthly 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](mailto:Patricia_Maxwell@ASAP.org)

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

*ASAP Connections* Editor: Patricia Maxwell