

ASAP to Celebrates 30 Years

by Patricia Maxwell

Imagine a day when information about Chiari and syringomyelia was not available. Today with multiple support groups, advocacy organizations, news sites and Google data, information is everywhere. However if you look back thirty years, you will not find desktop computers, the internet, smart phones or any of the common conveniences available today. It was a different story.



Barbara and Don White 1988

When Barbara White was diagnosed in 1983, with syringomyelia (SM), she immediately began researching. She contacted doctors, nurses and searched the library. Information was extremely limited. From 1983 to 1987 Barbara had a total of four surgeries to try and stop the progression. She was then told that nothing more could be done. Barb wrote, "For a week I had a pity party like you have never seen. I wallowed in that pity and just wanted to die. Somehow my husband and family got me past that crisis to the point of being angry. It took anger for me to realize that Don and I could no longer just talk about an organization, but we had to take action. We could no longer wait for someone else to act for people with syringomyelia."

With the help of family and friends, the Whites took a leap of faith and started ASAP. Barbara and an early supporter, Candace Morse, knew they wanted the initials a.s.a.p. to be part of the organization name to show how urgently help was needed. Sorting out the legal requirements for incorporation and obtaining the 501(c)(3) tax status were just hurdles to get over before the real work could begin. Finally, the American Syringomyelia Alliance Project was officially incorporated on May 31, 1988.

Early on Barbara contacted the National Organization for Rare Diseases. Although they did not have much information about the disorder, they put her in contact with several others who shared her diagnosis. She also discovered the Bobby Jones Open, a group of golfers who had gathered every year since 1979 to play golf in honor of the original 'Bob' who also had syringomyelia. It presented a perfect opportunity to meet not only other syringomyeliacs (as they called themselves) but also start a relationship

that would unite both groups. In the summer of 1988, Barb and Don White attended the Bobby Jones Open in Michigan where they met others with SM. Robert A Jones, better known as 'Computer Bob' among the golfers, served on the ASAP Board of Directors for many years.

After reading a journal article on syringomyelia, Barbara contacted the author, Bernard Williams, a consultant neurological surgeon in Birmingham, England. He made several trips to the US and recorded lectures the organization used for education. He also introduced them to ANTS, a support group founded in England by Ann Conroy, another syringomyelia warrior.

During the ASAP Chiari & Syringomyelia Conference in Long Island, New York this past July, ASAP joined with organizations in England, France, Italy, Japan and China to develop an international consortium to promote research, education and support around the world. As we look forward to 2018, ASAP will begin making plans to celebrate 30 years of service to the syringomyelia and Chiari community. Please join us as we continue our mission to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders while we find the cure.



Bobby Jones Open meeting in 1988

A Word From Our President



I truly can't believe that fall is upon us. The leaves are changing, pumpkin scents fill the air and seasonal flavors are all about us signaling the coming holiday season. For us here at ASAP, it also means the 2018 conference is around the corner and planning is well underway.

The past year was a very busy one. In addition to our regular programs, we held our largest conference ever with over 80 doctors speaking from the US and around the world (England, Australia, France, Italy, China, Japan and Germany). I extend my thanks to our hosts, Dr Paolo Bolognese and Dr Roger Kula for their selfless commitment of time and effort that went into this conference. We had speakers in two rooms running simultaneously, received the CNS Seal of Approval and CME accreditation. My thanks also to the doctors and medical professionals; they traveled great distances, donated their time and their knowledge to create this unique event. Once again they have demonstrated their unwavering commitment to our community. Lastly I thank the conference committee. The personal investment of our staff and volunteers is tremendous, without which this event would not exist. I thank all of these individuals, it is an honor for me to serve with all of them. Every year we hold a dinner for our speakers. We had a cake which read, "Alone we can do so little; together we can do so much" (Helen Keller). This quote rang true at this conference. It would be impossible without our dedicated doctors. They use their own resources to attend in the effort to help us. We are truly grateful to have such a caring community of specialists.

There are many exciting things coming up. Next year will be our 30th year and we will make some big announcements. Since we had so many contributors from around the world, we will continue with an international mind-set. This conference truly accomplished a lot. We will fill you in as we move forward.

Chiari and syringomyelia patients do not always show their battle scars. The diagnosis, surgeries and dealing with chronic pain in addition to coping with lifestyle changes affect us even when others do not notice. Years ago, I was told I have the look-good disease. I do my best to keep moving forward. However, feeling well for me is always a challenge.

Sameness can be monotonous; it can also be wonderful when people give year after year. We are so grateful for your generosity. If you gave last year, we hope you will want to give again. I hope everyone who reads the newsletter this year will contribute a few dollars, no amount is too small. ASAP does its best to avoid multiple campaigns throughout the year. I would prefer to ask once and save the expense of multiple mailings. If you, your family or a friend are affected with these disorders, then you know why I am asking for a donation. Please give this request serious thought and consider ASAP. Your gift, added to that of our many other contributors, can add up to real help for those with CM/SM and related disorders. ASAP has so much in store for 2018, and we do so much with the funds available: conference, programs, research, support and education, etc. Thank you for your kind consideration and generosity.

Gentle Hugs always,
Patrice
Patrice_Schaublin@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.

Patrice Schaublin (center) presented awards of appreciation to Ulrich Batzdorf (left) and Arnold Menezes (right) for 25 Years of Service on the ASAP Medical Advisory Board

How to Help a Friend or Family Member Living with a Chronic Illness

If someone you love is diagnosed with cancer or a life-threatening disease, you may feel desperate and completely helpless. But it doesn't have to be that way.

Research has shown us that family and friends can play a huge role in helping patients deal with a chronic illness.

When a person is suffering from a chronic illness, it's important that they feel truly cared about. What matters most is how people interact with the sick person.

Here are some ways that patients and their families can get the kind of support they want from others:

Put an end to family secrets. In other words, honesty is still the best policy. We often try to protect our families and loved ones from bad news, but hiding a person's serious illness from the rest of the family can backfire. Communicate directly and be open with family members.

Include your children. Although their understanding of the situation may be limited, children still appreciate being told what's going on around them. Children can sometimes view themselves as the cause of problems or major events that happen around them. They may view a parent's illness as being caused by something they did. Be open, honest, let children know it's OK to ask questions. This will help relieve some of their anxiety. Remember, a child can be a great source of laughter and warmth for a sick individual.

Be selective. Everybody under the sun doesn't need to know about your illness or your loved one's illness. Choose who you care to share your news with carefully. Some relationships will prosper and some will become strained. What's important is that you feel that sharing the information with an individual will provide a stronger sense of support and strength.

Be clear about how family and friends can help. People want to feel useful. Don't be ashamed to ask for help or favors, such as cooking a meal or helping with the school carpool.

Finally, if someone you love is suffering from a chronic illness, learn about the disease, help out with daily errands and chores, and give emotional support. Sometimes we all need a shoulder to cry on.

[This article is courtesy by the American Psychological Association.]

www.ASAP.org

Walk and Roll for Chiari and Syringomyelia

Jessica's 2nd Annual - Gouverneur, New York

August 13



Jessica's 2nd Annual ASAP

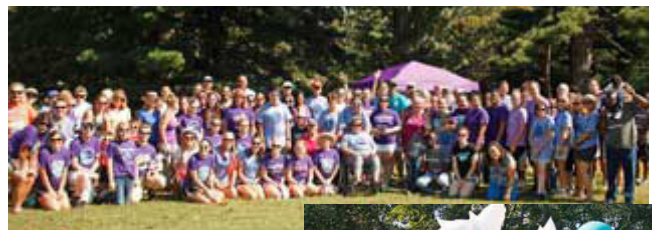
**WALK
& ROLL**

FOR A CURE
SYRINGOMYELIA & CHIARI
WWW.ASAP.ORG



Molly's 3rd Annual - Germantown, Maryland

September 16



Post-operative Decompression Volume Correlates with Outcome in the Chiari Type I

by John Oró MD

The goal of surgical decompression in persons with intractable symptoms from the Chiari I malformation is to alleviate crowding caused by cerebellar tonsillar herniation in the region of the foramen magnum. Expanding the posterior cranio-cervical volume can improve CSF flow and alleviate symptoms.

However, the correlation between the amount of CSF space surgically created and clinical improvement has not been well studied. In part, this due to the tedious nature of the current tools used to measure the pre- and post-operative posterior fossa and CSF space volumes.

In an article published online in the Journal of Neurosurgery: Pediatrics on February 17, 2017, researchers from the Division of Neurosurgery, Children's National Health System in Washington DC, describe the development of a "semiautomated program for calculating the 3D posterior fossa CSF volume." Using this technique, the authors determined the correlation of the posterior fossa and CSF space volumes (cisterna magna, prepontine cistern, and fourth ventricle) with the clinical outcome in 42 pediatric patients undergoing decompression surgery for CMI.

Posterior fossa and CSF volumes were measured on the axial T2-weighted MRI images on scans taken before and after surgical decompression. The change in these volumes were then correlated with the postoperative outcome in

"headache, syrinx, tonsillar descent, cervicomedullary kinking, and overall surgical success."

The study revealed that greater enlargement of the posterior fossa volume resulted in greater clinical improvement. In addition, enlargement of the cisterna magna also resulted in improved outcome. Furthermore, enlargement of the lower portion of the posterior fossa correlated with reduction in syrinx size. In the author's words:

"A statistically significant association was found between a larger increase in the total posterior fossa volume and the cisterna magna CSF volume after CM-I decompression and improvement in headache, tonsillar descent, and surgical outcome. When the caudal portion of the posterior fossa volume was isolated, larger volume increases were associated with statistically significant increases in syrinx and cervicomedullary kinking in addition to headache, tonsillar descent, and surgical outcome."

The authors also identified an area of future study: How large is large enough?

"Decompression volumes will need to be correlated with clinical outcomes in a prospective study before conclusions can be made on the optimal decompression size or technique."

Reference: Comparison of posterior fossa volumes and clinical outcomes after decompression of Chiari malformation Type I

ASAP History

When I took over as newsletter editor in 2000, I thought it would be a temporary solution until we found another volunteer. I was excited to create an informative, interesting publication that would educate and support our Chiari / syringomyelia community. It is amazing how fast seventeen years can go by when you're having fun. But this article is about the history of ASAP so let's get started.

The original ASAP newsletter was written by Barbara White. She typed a personal letter introducing herself, her story and why she started ASAP. The early letters were about the development of the organization, ideas for spreading awareness and the dreams that she hoped would someday come true. A plan was in place and the small grass roots group was in its early stage of expansion.

Then 1989 Candace Morse became the editor adding typesetting and pictures. But it wasn't until 1993 that a

member contest gave the newsletter a name, *Syringomyelia Connections*. Under the editorship of Angela Smith it grew even further taking on a more professional look. When Christian Barthol took over in 1994, computer software added another dimension. Christian focused on medical information contributed by doctors and expanding the range of subject matter to include genetics, associated disorders and a question and answer section.

Starting with a subscriber base of 50, we have grown to more than 10,000 over the years. In 2001, in order to better represent the community, the newsletter continued its evolution and became *ASAP Connections*. The newsletter has unified ASAP into a strong organization. Members are invited to share their stories, write articles that would be beneficial to others or just let us know how we are doing. Your input makes for a better publication, email Patricia_Maxwell@ASAP.org with comments, articles or suggestions.

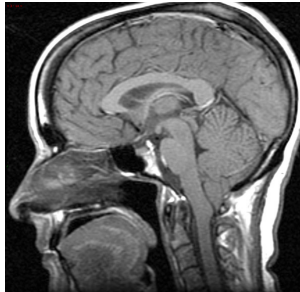
HISTORICAL VIGNETTES

by Graham Flint, MD

I noted a comment in our last newsletter (Ann Conroy Trust), from one of our readers. She was generously complimentary about our annual convention but went on to say how Arnold Chiari had had quite an effect upon her family's life. This reminded me that it may sometimes be helpful if neurosurgeons can find time to explain to their patients not only the meaning of the term Arnold-Chiari malformation but also its origins. In compiling this account I referred to books dealing with the origin of medical terms and the history of medicine. The most useful source, however, was a website known as whonamedit.com. I would recommend this site to anyone interested in reading more about the individuals mentioned below or, for that matter, many other medical pioneers.

Who was Arnold Chiari?

The expression Arnold Chiari is what we refer to as an eponymous term. By this we mean that the name of an individual is given to a disease. Usually that individual was the first person to describe the condition, or to do so in any detail. Another well-known example in the field of neurology is Parkinson's disease. Just occasionally a condition is named after an individual patient and from time to time an eponym is the name of a place. The etymological meaning of the word eponym is "name placed upon."



Sometimes more than one person is recognized as having described a condition and more than one name may then be applied to the disorder. This is just the case with hindbrain hernias. Arnold and Chiari were two different individuals who both made contributions to our understanding of the condition. Chiari is considered to have made the greater contribution which is why the eponym is commonly abbreviated to the Chiari malformation. In truth it was a third person, by the name of Cleland, who first described hindbrain hernias and the alternative eponym of Cleland-Chiari syndrome has been proposed by some.

There is yet another eponym which is seldom used but which a syringomyelia "aficionado" should be aware of. This term is Morvan's disease or Morvan's syndrome. Both expressions are sometimes used as synonyms for syringomyelia but they really refer to a specific and rare complication of the disease. Someone with Morvan's syndrome will have developed ulcers on the fingers and other changes affecting the skin and nails of the hands. The underlying bones may also be affected. These findings are distinct from the more common features of loss of pain and temperature sensation, with the resultant cuts and burns, which we sometimes see with syringomyelia.

John Cleland was born in 1835. He studied medicine in Edinburgh, becoming a doctor in 1856. He was appointed as Professor of Anatomy in Glasgow in 1877. He published extensively and in 1883 was the first to describe what we now know as the Chiari malformation. Cleland died in 1925.



Hans Chiari was born in Vienna in 1851. In 1883 he became Professor of Pathological Anatomy in Prague. In 1906 he moved and took up a similar post in Strasburg. He, too, wrote and published extensively. Whilst in Prague he produced, in 1891 his first description of the malformation that now bears his name. He published a more detailed account of the abnormality in 1895 and again in 1896. Chiari acknowledged Cleland's contribution to our understanding of hindbrain abnormalities, in his publication of 1895. Chiari died in 1916.



Julius Arnold was born in Zurich in 1835. He qualified as a doctor of medicine in 1859. In 1866 he became Professor of Pathological Anatomy in Heidelberg. Like Cleland and Chiari he produced a large number of publications in his lifetime. In 1894, three years after Chiari's original article appeared, Arnold also described an abnormality at the craniovertebral junction, affecting the brain stem, fourth ventricle and cerebellum. Two of Arnold's students later emphasised the associated bony abnormalities at the base of the skull and it was they who coined the term Arnold-Chiari malformation. Arnold died in 1915.



Augustine Morvan was born in 1819. He studied medicine in Brest and then Paris. He qualified as a doctor in 1843. Morvan was another prolific writer and he described the syndrome that bears his name in 1883. He gave, at the same time, a thorough description of syringomyelia. Morvan died in 1897.



So there we have it, a good European mix of French, Austrian, German and Scottish experts, all contributing to our understanding of hindbrain hernias. The latter term, of course, was coined by an Englishman, our own Bernard Williams. In common with our other "heroes," Bernard wrote extensively about syringomyelia and other neurosurgical conditions. He hoped that, by adopting the expression hindbrain hernia, we might avoid some of the confusion created by the use of eponyms. Eponyms may honour the contributions made by medical practitioners in the past but they do little to describe the nature of the conditions to which they refer.

[Dr Flint is a neurosurgeon practicing in Birmingham, England. He works closely with the Ann Conroy Trust, a UK based charity that provides support for people living with SM/CM.]

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

My Son

Tiffany Hill

Tasha Nelson

Tina Whitman

Andrew Brodbelt

Tough Mudder Donors

Mary Ann Leventhal

Robert Marshalkowski Jr

Benjamin Marshalkowski

Frannie

Becky & Jim Sprunger & family

Brenda Jarmon

Vernal Jarmon

Emmett Douglas Priest

Cheryl Priest

Rachel Rucker

Clara Crosby

Jen Adair

Cynthia Jankowski

Kristen Woods

Denise Behary

Lynda Turbidity

Denise Kilmer

Ellen Muller

Jane Turner

Catherine Eichelberger

Ruth Angevine

Alivia Juliana

Marie Juliana

Michael Kirlin's 27th Birthday

Dennis & Diane Kirlin

Sharon Avni

Irene Reiss

Jaclyn Geddes

JoEllen Geddes

Lexi Feldman

Lyn & Richard Feldmann

John Moore

Gabrielle Evans

In Memory of

Donor

Bob Sletten

Becky & Jim Sprunger & family

Betty Linscott

Daniel Kress

Lynn Corsino

Maryann Zaremba

Sheila Roy

Betty & Richard Green

Don Green

Edward & May Coffin

Edwin Wyman

Esther Lowell

Gail Appleton

Joan & Robert Lacasse

Mary & Richard Wallace

William & Katherine Perry

Vicki Sells

Susan Norton

Barbara Altshuler

Robert & Janice Howe

Martha Morrill

Margaret Ayotte

Louise Linscott

John Coleman

JoAnne, Don & Kelly Govanucci

Martha Filipovic

Sylvia & Jim Coulter

Mary & Pat Kelly

Joe Green

Diane Linscott

Patricia Schneider

Mr. & Mrs. Peter Hoy

Margaret Schneider

Virginia Ferrenberg

Marilyn Delaney

Friends at Bernstein Shur

Brian Turner

Sheila Faherty

David Kaufman

Stephen & Arlene Sharkey

Donalda (Dawn) Wolfe

Sandra Haines

Jane Anderson

Richard & Heidi Diven

Bertil Hurt

Rachel & John Kasianowicz

Richard Kloss

Carol & David Fordham

Diantha Duvall

H L & M M Orloff

Lynn Masters

Richard Nemec

Larry Kloss

In Memory of

Donor

Harry Watson

Roberta Watson

Diane Strauser

Michelle Strauser

Donna Nelms Kelly

Carol Wilhite

Steve Kelly

Lee & Jeannie Monasmith

Nora Glass

Pamela Ladd

Robert & Kay Eversole

Elizabeth Vogelsang

Ann Syrett

Fred Jacobeit

Ron & Susan Brauer

Anatoli Boyko

Audrey Smith

Brent Bronnenberg

Dennis & Bette Kirkman

Joan Swartz

Robert Scholoss

Ira Schloss

Brenda Schloss

Jim Brown

JoAnn Brown

Elliott Sachs

Stephen & Arlene Sharkey

Helen Jones

Marilyn Jones

Mary Carol Menotti

Nicholas Menotti

Mary Rapotas

Ann Priester

The Lyons Family

Megan Reynolds

Nigel Reynolds

Giorgina Bolognese

Lynn Cohen

Alice & Stuart Cohen & Family

Michael Morrell

Joyce White

Patricia Maxwell

Judy Hunt

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

Staff:

Patricia Maxwell

Patricia_Maxwell@ASAP.org

Jamie Mayhan

Jamie_Mayhan@ASAP.org



"Thank You for Supporting ASAP!"

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

Name _____

Address _____

City _____ State _____ Zip _____

Email _____ Phone # _____

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

☐ No, please remove me from your mailing list.

I would like to make a tax-deductible donation to support ASAP programs & research.

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

Credit Card ☐ MasterCard ☐ Visa ☐ Discover ☐ American Express

Card # _____

Name of Cardholder _____

Signature _____

Expiration Date _____ Security Code _____ Amount \$ _____

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

Shop our Online Store for Great Gift Ideas

<http://asap.org/index.php/store/>



Items shown: Stainless steel water bottles \$6 each, Post it notes 5 for \$5, Folding cloth frisbee with storage bag \$3 each, Lanyard \$5 each, color changing water bottle \$5 each, cloth shopping bags \$3 each, glow in the dark awareness bracelets 5 for \$6. Find these and more at www.ASAP.org/intex.php/store/

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

Patrice Schaublin, President
Annie Chapman, Treasurer
Eric Berning, Secretary
Paolo Bolognese, MD
Bridget Borys
John Caemmerer
Gerald Grant, MD FACS
Robert Keating, MD
Richard Simon
Cathy Tufts



ASAP Medical Advisory Board

Robert Keating, MD - Chair
Children's National Medical Center
Ann Berger, MD
National Institutes of Health
Timothy George, MD
Dell Children's
Gerald Grant, MD - Research Chair
Duke Medical Center
John Heiss, MD
NIH/NINDS
Bermans Iskandar, MD
University of Wisconsin-Madison
Roger Kula, MD
North Shore Univ Hospital
Cormac Maher, MD
Univ of Michigan Health Systems
Arnold Menezes, MD
Univ Iowa Hospitals & Clinics
Erol Veznedaroglu, MD
Drexel

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