

Connections

"To Improve the Lives ... While We Find the Cure"



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American
Syringomyelia
Alliance
Project, Inc.

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Research, Condition and Disease Categorization (RCDC) Process

For many months, the National Institutes of Health has been explaining the new RCDC process and how it will change the way the NIH reports on the research it funds.

RCDC is part of a wider NIH effort to enhance public accessibility to reports, data, and analyses of NIH research activities.

The NIH recently launched a new web site called RePORT (the Research Portfolio Online Tool, <http://report.nih.gov>). RePORT gives the public a single access point to quickly and easily find data, including information on NIH expenditures and the results of NIH-supported research.

RCDC results will show the amount NIH funded in each of the same 215 categories it has historically reported to Congress and the public. The results will be accessible through the RePORT web site. Each category will provide detailed information, including for the first time a complete list of all NIH-funded projects included in that category.

The RCDC results tables will be one of six features within the RePORT site. Other features include the Extramural Data Book. In 2009, the NIH will add an enhanced version of CRISP-on-the-Web to the RePORT site. This new tool, called RePORTER (RePORT Expenditures and Results), will include RCDC categories and project listings.

RePORTER will enable the public to search for NIH-funded research information and find information associated with funded projects, including budget information and links to publications and patents.

For more details, please see the web site:
http://rcdc.nih.gov/RCDC_OHM/Default.aspx

[Information provided courtesy of U.S. Food and Drug Administration]

FDA Teams up with WebMD for New Online Consumer Health Information

New Partnership to Inform and Educate Tens of Millions of Americans

The U.S. Food and Drug Administration and WebMD announced a collaboration that expands consumers' access to the agency's timely and reliable important health information. This joint effort reflects the FDA's emphasis on using innovative, technology-based strategies to carry out its foremost mission, which is to promote and to protect the public health.

WebMD, which attracts nearly 50 million unique visitors each month, provides consumers with credible and timely health news and information.

"We are enthusiastic about this collaboration with WebMD because it will enable us to reach more consumers with accurate, science-based information that can help them improve their health," said Andrew C. von Eschenbach, MD, commissioner of food and drugs. "This is an important step forward in our effort to form partnerships to help bring timely safety alerts and other public health information to a wider audience in the most effective and convenient way."

The partnership includes:

A new online consumer health information resource on WebMD.com (www.webmd.com/fda): Consumers can access information on the safety of FDA-regulated products, including food, medicine and cosmetics, as well as learn how to report problems involving the safety of these products directly to the FDA. In addition, WebMD will bring the FDA public health alerts to all WebMD registered users and site visitors who request them. The cross-linked joint resource will also feature

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ASAP

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Bobby Jones Open College Scholarship

by Patricia Maxwell

Through various programs the Bobby Jones Open (BJO) has partnered with ASAP for over 18 years to improve the lives of persons affected by syringomyelia, Chiari malformation and related disorders. The BJO College Scholarship has assisted ASAP members with their education since 2003. During that time 15 students have received \$37,000 in financial aid.

This year's recipients chosen from 20 applications include one new and four renewal students: Caitlin Sevigny, Shellee Syrewicze, Melissa Murray, Jamie Rose and Shauna Sedler. All are full time students attending colleges in either Michigan, Maine, Missouri or Massachusetts. The application process is open to people diagnosed with syringomyelia or Chiari malformation or have a parent with the disorder and who are members of ASAP for at least six months before applying.

New applications must be received January 15 through May 15. The renewal applications period is May 15 through June 15. Students must provide medical certification of his/her or parent's diagnosis. Other criteria include a completed application form, essay and financial information. Those interested in learning more about the scholarship can download the application and informational brochure at **www.ASAP.org** or contact the ASAP office.

To insure fairness in the ranking of the applications, the BJO has chosen College Foundation, Inc. (CFI) to review all applications. CFI is an independent nonprofit organization dedicated to helping students achieve their college goals. All applications will be mailed directly to CFI. Your confidentiality is important to us and CFI will use reasonable safeguards to protect the information submitted.

Due to the death of Robert A Jones there were a few problems with the scholarship process in 2008. Robert D Jones, president of the BJO, is working hard to correct these issues and alleviate them in the future. We are grateful for the continued support of the Bobby Jones Open.

ASAP Outreach Telephone Seminar

March 17, 2009
8:00 PM Eastern

Free one-hour presentation featuring keynote speaker:
Diane Mueller, PhD

Thinking about having a baby? Women with Chiari malformation and syringomyelia have special concerns and questions about pregnancy. You will not want to miss this special presentation.

To take part in this Outreach Telephone Seminar register online <http://www.asap.org/2008/teleconference.html> or call the Longview business office.

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.

A Word from Our CEO

by Dick Hellner

Voluntarism – A Key Growth Strategy

How do many small and mid-size nonprofits effectively pursue their missions and expand their service programs to help more people? How do they keep operating expenses low and compete favorably with larger charities in dedicating more resources to those who need their help? Among the number of techniques used, one stands out above all others – voluntarism.

Voluntarism is defined as the principle or practice of using the collective, coordinated work of people who freely give their time without financial compensation to accomplish a worthwhile goal, usually helping others in the community.

Starting with its founders, Don and Barbara White, ASAP has a long, twenty-year history of successfully turning the generous gifts of time and talent of members to help the organization meet the needs of the growing SM and CM community. Today's volunteers stand on the shoulders of the many selfless men and women who came before them in building this effective organization.

Today, while we enjoy the efforts of many wonderful volunteers, more are desperately needed:

- To help current volunteers and guard against burnout
- To further minimize cost to make up for diminished giving in an uncertain economy
- To respond to new challenges and opportunities
- To add a broader level of talent and experience

Please consider completing the volunteer form which you will find as an insert in this newsletter. Mail it to our Longview, TX office. The form is also available on our web site: <http://www.asap.org/resources/volunteer.html>

Thank you!



The Art of Fundraising

by Arnie Hulteen

One of the top strategies to develop the revenue needed to help ASAP fulfill its mission of service to the SM and CM community is the work that members do to organize and conduct local fundraising events. A strong additional benefit to these activities is the development of local name recognition and public education about these conditions.

Especially in this time of financial uncertainty, anything that community members can do to support each other locally and help others around the country through ASAP's vital programs will help all of us endure this unsettling period. While the winter and early spring are generally not amenable to some kinds of events, many others can be conducted with exceptionally good results. Here are some suggestions that will hopefully spur you, your family and your community to help throughout this economically challenging near-term future.

Dinner Dances

Costume Balls: Pick a theme that blends with your organization and have a "ball." From movie themes to songs or even your role model, this gets donors dressed and ready for fun.

Fashion Shows: Partner with one or more clothing retailers in your community. In addition to the revenue produced through ticket sales, this is a wonderful live auction opportunity to offer the merchandise of the sponsoring clothing retailers and others.

Secondhand Rose Show: Use items from your local thrift store or combine with another local charity that has a thrift store and split the profits.

Events for the Whole Family

Walk-A-Thons / Pet Walks: Start and end the walk in the parking lot of your local newspaper and you can gain extra publicity by teaming up with the media. If expenses allow, have a tent with vendors, kid's activities and other street fair type events and create a full day of fun and great exposure for ASAP. You could purchase items through ASAP's web site and sell them at a higher cost to benefit ASAP, i.e., ASAP mugs, tee shirts, Christmas cards and the like. Don't forget to have a booth/table to include ASAP materials that help explain ASAP's mission. Give donors a way to donate through brochures, remittance envelopes and most importantly, display ASAP's web address for more information.

Other A-Thons: Walk, climb, dance, cut hair, read books, ride bikes, call, ride horses, fishing competitions or do a



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You Asked...We Listened

ASAP has developed a convenient way to make periodic donations to help all those who are affected by CM and SM. Visit the donations page on our web site www.ASAP.org and choose from among the various options including monthly, bimonthly and quarterly. It's that simple; the rest is done automatically unless or until you decide to make a change.

Ask The Experts

Question and Answer - Scoliosis and Tethered Cord

Question: When my daughter was three she had a 37° scoliosis, Chiari and syringomyelia. She had two decompressions, the second one worked. Every year her scoliosis got 10° better and got down to 15°. Then, this year it went up to 22°. I was told to look into tethered cord that may be causing the scoliosis. Is it better to untether the spinal cord when you are young? If it's not tethered cord what else could it be?

Dr. Oró: We need to talk about a variety of possibilities. Looking at the syrinx, is it persistent and why? But there is a new concept that I think we'll hear more about concerning tethered cord, even though your spinal cord ends in a normal position. The classic hidden tethered cord meant that your spinal cord was held down at the bottom of your spine. As you grow, your spine grows more than the nerves and spinal cord. The spinal cord actually moves up as we get older and that's in part answer to the question of why tethered cord might occur later on in life.

There is also a new challenging concept right now but we don't have enough solid information to talk about it yet. It appears that surgeons from Barcelona, Spain were the first to make this observation. In a study of twenty patients, some with syringomyelia, some with syringomyelia and Chiari they released the spinal cord, even though it was in the normal position. How do you make that diagnosis? It's not very easy to make if it's a normal MRI scan. Unfortunately, there's a lot lacking in the report. It's very pioneering work, but it's not very thorough. Some of these people had dramatic improvement in their neurologic symptoms with snipping this band, even though the cord was in the normal position. And it was also associated with scoliosis, bladder problems, numbness of the feet and some people could not bend forward very well and touch their toes. I hope the people at the Chiari Institute will be able to tell us more about it because they probably have the most experience so far.

Dr. Ellenbogen: There's a neurosurgeon in Portland, Oregon who does about 150 tethered cord releases a year. I do about 50 a year. It is interesting that 80 miles away there seems to be a higher incidence of this. To tell you that we have answers is really quite false. It's a huge controversy in neurological surgery that the spinal cord in the normal position causes problems. If the spinal cord is low lying, we do know that if you snip it, which is fairly safe with younger patients, they won't go on to develop neurologic deficits. Most of the time it doesn't retether. However if you wait until they get a neurologic deficit, the outcome may not be as positive. For example, I had a ten-year-old soccer player who lost the function of his leg. When we snipped the cord, he got better but he still had a numb leg. If you do it before there are problems, the result is better. But untethering the spinal cord at the normal level is still an extremely controversial subject that people debate

and we just don't know the answer. We're not taking either side; we're just trying to get the current data out there.

Dr. Oró: I think what Dr. Ellenbogen is referring to in terms of the Oregon neurosurgeon is that these are children who have lost bladder control at school. It's not a Chiari or syringomyelia issue, but there is this group of young children who are wetting themselves at school who seem to be responding to this procedure.

Dr. Ellenbogen: Yes, that's correct.

Dr. Oró: The other thing is that there are a growing number of people who have had release of tethered cord in the normal position. In them it made a big change in their life. I agree with Dr. Ellenbogen, we need some hard evidence guiding us as to who will respond and who wouldn't.

Dr. Ellenbogen: I totally agree. It's like a lot of things in medicine. We can give a simple drug for a lot of diseases and only a certain percentage of people are going to get better; nothing works 100% for everybody.

[Transcript from the 2007 ASAP Conference, Seattle, WA.]

Dr. Richard G. Ellenbogen is Professor of Neurological Surgery at the University of Washington

Dr. John J. Oró is a neurosurgeon experienced in the treatment of Chiari I malformation. In 2005, he founded The Chiari Treatment Center in Aurora, Colorado]



Thank You, Rich

Richard Zimmer has been an active member of ASAP for 20 years, serving our mission in multiple ways. His valuable personal experience has been shared with others through both the peer support program and conferences. In November 2004, he was elected to the Board of Directors and re-elected to a second term in 2007. However due to continuing health issues he found it necessary to resign this position December 31, 2008.

Judy Hunt, ASAP President said, "I have been honored to serve on the Board with Rich. His commitment to represent ASAP members as a Director has been an invaluable asset to this community."

As a Board member Rich fought for his peers and programs to improve the lives of those affected by syringomyelia and Chiari. We are grateful to Rich for his passion, dedication, leadership and business experience.

FDA Teams up with WebMD

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FDA's Consumer Updates—timely and easy-to-read articles that are also posted on the FDA's main consumer web page (www.fda.gov/consumer).

FDA Consumer Updates will also be featured at least three times a year in WebMD's bimonthly magazine, which reaches nearly nine million consumers. The magazine is distributed to physician office waiting rooms across the country.

"As a leading brand of health information, we are pleased to be partnering with the FDA to provide consumers with public health and safety information, direct from the source," says Wayne Gattinella, WebMD president and chief executive officer. "This important partnership is consistent with WebMD's longstanding mission of providing for Americans access to credible and relevant health information."

Consumers have increasingly consulted all types of sources to find health information, and the Internet is their fastest growing resource, according to a national study released in August 2008 by the Center for Studying Health System Change. Researchers found that 32 percent of American consumers—70 million adults—conducted online health searches in 2007, compared with 16 percent in 2001.

The study also found that most consumers who researched health concerns reported positive outcomes. More than half of those surveyed said the information changed their overall approach to maintaining their health. Four in five said the information helped them better understand how to treat an illness or condition.

The complete terms and components of the partnership are described in a Memorandum of Understanding which is available online at <http://www.accessdata.fda.gov/scripts/oc/ohrms/advdisplay.cfm>

[Information provided courtesy of U.S. Food and Drug Administration]

**Save the Date
2009 Annual Conference
July 15 - 18**

**Sheraton Madison Hotel
Madison, Wisconsin**

FDA Approves New Drug to Alleviate Moderate to Severe Pain

The U.S. Food and Drug Administration has approved Tapentadol hydrochloride, an immediate-release oral tablet for the relief of moderate to severe acute pain.

Tapentadol is a centrally-acting synthetic analgesic that is available in doses of 50 mg, 75 mg, or 100 mg.

"This approval offers health care professionals an additional choice for treating moderate to severe acute pain," said John Jenkins, MD, director of the office of new drugs in the FDA's Center for Drug Evaluation and Research.

Tapentadol acts in two ways, opioid (narcotic) and non-opioid. It affects the brain and body primarily by activating opioid receptors in the brain, spinal cord and gastrointestinal tract. In addition, Tapentadol inhibits the reuptake of the brain chemical norepinephrine which possibly has an analgesic effect.

Acute pain is a symptom of many medical conditions and can significantly interfere with a person's quality of life and general functioning. Opioids are considered safe and effective in selected patients but can cause dependence, abuse, and addiction. All patients treated with opioids require careful monitoring by their health care professional for signs of abuse and addiction, and to determine when opioid analgesics are no longer needed.

The most common side effects from Tapentadol are nausea, dizziness, vomiting, and sleepiness. The labeling for Tapentadol includes warnings about the risk of respiratory depression; addictive depressive effects on the central nervous system when taken with alcohol, other opioids, or illicit drugs; and abuse potential.

Tapentadol is manufactured by Janssen Ortho, LLC, Gurabo, PR.

[Information provided courtesy of U.S. Food and Drug Administration]

[Editor's Note: The information found in this newsletter should not be used as a substitute for medical advice from a certified medical professional. It is provided purely for informative purposes.]

**www.ASAP.org
1-800-ASAP-282**

Member Profile

by Patricia Maxwell

Every morning hundreds of children wake up with a pounding headache. They sit on the sidelines as they watch their friends, unable to participate due to pain and fatigue. Parents, seeking answers, make numerous appointments with the pediatrician. Sometimes told it is psychosomatic or temporary, they are left to their own devices and the Internet to find answers. A scenario played out far too often—ASAP members are discovering creative ways to combat the isolation and reach the public with our mission. This is Cathleen's story.

An adventurous nine-year-old, Cathleen loves softball and swimming, collects snow globes, excels in math, and would prefer spelling was dropped from the classroom agenda. She looks forward to one day playing the trombone in the high school band. But unlike her friends, she lives with chronic pain. The family doctor was determined to find the cause of her symptoms but it was a rocky road. After visits to multiple physicians, an MRI finally revealed the answer: Chiari malformation. The family was relieved but still in the dark. Like most, they had never heard of this disorder.

Cathleen's mother, Sara, spends hours searching the web. She credits the ASAP message board with helping her to find a specialist that has been able to answer many of her questions. She has shared this information with others who have also been diagnosed in her small town. She is helping others to bypass the months and years of searching for help.



Sara desperately wanted to raise awareness about the disorder her daughter battles daily. After brainstorming with Arnie Hulteen, ASAP Chief Development Officer, an idea began to take form. Working with a family friend who owns a print shop, they designed a banner which now hangs in front of

her store. It wasn't long before an old friend driving past noticed the sign. She had just been diagnosed and couldn't believe what she was seeing. Sara was able to help her friend skip all the disappointing doctor visits by sharing her information and experience.

It is not easy keeping Cathleen's life normal. A 504 plan is in effect at school that allows her to have two sets of books—one in the classroom and one at home. She is excluded from certain gym activities and is not allowed to lift more than 15 pounds. Cathleen and her family have faced multiple challenges in the last two years and they realize it is only the beginning.

Sara knows that awareness is the key to finding a cure and will continue her endeavors toward that end. The family has taken their sign to local support group meetings. Sara is having magnetic awareness ribbons made to sell as a fundraiser. Gabriella, Cathleen's older sister, published an article for the local newspaper about the struggles the family is facing and what they are doing to overcome them. The family battles daily to maintain a positive attitude. They believe the key component to emotional stability is a strong family foundation and are working together to provide Cathleen with a safe haven.



Florida Dad Turns Hobby into Fulltime Fundraiser

by Patricia Maxwell

Working Toward a Cure

Stuart enjoys tying flies almost as much as he enjoys fly fishing. So he decided to turn his tying interests into a revenue stream for syringomyelia and Chiari malformation research. His twin daughters Hope and Holly suffer from several neurological conditions including syringomyelia, Chiari malformation, intracranial hypertension and chronic pain, disorders that have caused stress in the family's lives but also brought out strength, love and courage.

A few years ago Holly decided not to sit idly by and allow her condition to determine her future. Hope was in full support, excited and energetic. The girls decided to raise money to fund medical research. Holly's goal is to raise

\$20,000 before she graduates from high school. With help from their family and friends they have held several annual yard sales, sold hand-made bracelets, addressed community organizations, manned booths at local trade shows, and held fundraisers at their school.

Proud of his girls' efforts and wanting to help them reach their goal, Stuart designed a web site to sell his old Florida flies. Patterson Saltwater Flies donates all net proceeds from the sale of merchandise to research through the American Syringomyelia Alliance Project.

For more information about Stuart's endeavor visit www.pattersonsaltwaterflies.com

Awareness and Fundraising

Spaghetti Dinner

provided by Christine Marchessano

On October 3 the South Jersey Chiari Awareness Initiative hosted the first annual spaghetti dinner and auction, which successfully brought much needed awareness to the Little Egg Harbor community. Although this was Christine Marchesano's first endeavor, she raised \$4,000 for ASAP. Planning for the event which began in April helped Christine to learn firsthand how to reach out to her community for support in order to turn her dream into a reality.

Her incentive was very personal. Christine said, "Raising awareness about Chiari I, cranial settling and EDS and putting all my energy into an organized function, made it possible for me to feel vindicated. Even with physical limitations, I conquered and survived." When Christine acted on a nagging thought to get up and do something, she wrote a letter to the township committee and Mayor Scott Stites about others living with Chiari malformation and the necessity to raise awareness in the community.

As a result, she received a phone call from Deputy Mayor John Kehm, who was also the chief Masonic Lodge brother. He offered to do a fundraiser for the cause. She jumped on the idea and together they decided to organize a spaghetti dinner. Christine said, "The Masonic Lodge of Tuckerton, NJ, is made up of pretty amazing people who make things happen and have a passion for helping others. They also know how to have fun."

It was a night of celebration, fun, hope, community, discovery, awareness, and reality all wrapped into one. The

event which was attended by over 300 people included a live raffle and auction consisting of over 120 items. When Christine started to reach out to the community in late June, slowly but steadily the donations grew.

The highlight of the evening came when Assemblyman Brian Rumpf presented Christine with the New Jersey state proclamation that will be introduced to the legislature in Trenton. This is an effort to establish Chiari legislative bills that will address many issues pertaining to the disorder. Christine was excited to learn that from now on, April 10 has been declared as Chiari Awareness Day in Little Egg Harbor, New Jersey.

The Tidal Wave Band of South Jersey donated their time and talent providing the entertainment for the evening. Christine has been a follower of the band since 2005, developing a close friendship with its members. They were there for her before she became ill, when she was first diagnosed and offered their support when she underwent surgery. Pictures from the spaghetti dinner can be viewed on the band's web site: www.tidalwaveband.com/chiari/chiarihome.html

Christine credits Patrice Schaublin for providing the expertise to transform her ideas into a successful event. She would also like to thank Mark McKairnes, Arnie Hulteen, Ellie McCallum and Jamie Mayhan for their assistance. Special thanks to the Masonic Lodge and many other volunteers who live in the LEH community. Additional recognition is extended to the following companies that donated the food and drink—BJ's, Shoprite, Costco, ACME, Bruno's Meat Market, Shopping Bag and Sea Oakes Country Club.



Walk-a-thon

by Candy Reinert

In September, The Chiari People of PA support group held a Walk For a Cure and Awareness event in Reading, PA. The mall was the perfect location, sheltering the participants from the weather. ASAP CEO Dick Hellner and Board member Patrice Schaublin were on hand to open the event. It was a special time for everyone involved. Events like this give us all hope - hope in each other, hope in our community and hope that together we can make a difference.

Approximately 120 friends and family came together to learn more about Chiari and syringomyelia, while raising funds to be used toward research. The day was so much more than a walk. Along with it, the silent auction, raffles, a bake sale, and cotton candy sales, we raised close to \$6,000. The kids in attendance worked very hard on

making 65 soft travel pillows and "Thinking about you" cards for Chiari patients having surgery at North Shore University Hospital. The manager from Funland (an inflatable play area in the mall) even opened an hour early at no cost, to let the little ones bounce off some of the cotton candy they had for breakfast.

All in all everybody went away with a new appreciation for what it is like to live with Chiari and syringomyelia. They got a glimpse into the pain that we feel every day while checking out our Art of Pain wall. Families became closer and new friends were made. Most importantly they put us a step closer to finding a cure and learning how they can help spread the word. Each single voice can be a choir for our cause. We look forward to seeing more of you attend next year.

AZ Syringo Chiari Support Group

by Debbie Juengel

We had a wonderful presentation from Power Paws at our Oct. 16th meeting. They covered all the different types of service dogs they train. We also were treated with a demonstration from two puppies in training. Quite impressive!

Here is a list of the different type of dogs:

Assistance Dogs - These dogs are skilled to do many tasks including:

- Turning light switches on and off
- Opening and closing doors
- Retrieving items that have been dropped
- Helping with household chores, such as stripping bed linens
- Walking - Balance issues with special harness
- And above all, providing love and companionship

Hearing Dogs

- Hearing dogs serve as the ears for people who are deaf or hard of hearing. These dogs alert their deaf partner to sounds such as phones ringing, knocks at doors, timers, and fire alarms.

Psych/Social Dogs

- These dogs help people with psychological disabilities, such as fears, anxiety and post-traumatic stress disorder. Many people are able to lead more normal lives with the assistance these dogs provide.

Home Helpmates

- Skilled dogs that provide the same assistance as service dogs, but are used for people who have in-home attendant care. These dogs do not have public access rights.

Therapy Dogs

- Dogs that have the temperament to handle the hospital atmosphere for patient rehabilitation purposes. They have been prescribed by the doctor as part of occupational or physical therapy.

Animal-Assisted Therapy Dogs

- Animal-Assisted Therapy (AAT) is a goal-directed intervention in which an animal meeting specific criteria is an integral part of the treatment process. AAT is delivered and/or directed by a health/human service provider. AAT is designed to promote improvement in physical, social, emotional, and/or cognitive functioning. AAT is provided in a variety of settings and may be group or individual in nature.

They also talked about volunteer opportunities available including puppy raiser, puppy petters, or you can sponsor a puppy.

Thanks to Kathy Donohoe for arranging this wonderful speaker! We look forward to watching you & Allie (her service dog) progress.

Meet the Medical Advisory Board

Roger W. Kula, MD



Roger W. Kula, MD, completed medical school in 1970 at The Johns Hopkins University School of Medicine in Baltimore, Maryland. He underwent his internal medicine training at The New York Hospital-Cornell Medical Center. His neurology training continued at the University of California Hospitals, San Francisco, where his exposure to the influence of then-chairman Robert A. Fishman, MD, first stimulated his interest in spinal fluid physiology. He completed his formal residency training at the Medical Neurology Branch of the National Institute of Neurological Diseases and Stroke, Bethesda, Maryland, in 1975, where he continued training in neuromuscular diseases under the mentorship of W. King Engel, MD.

In 1977, Kula returned to New York to establish a neuromuscular disease program at the SUNY Health Science Center at Brooklyn as assistant professor of neurology. He was certified by the American Board of Internal Medicine in 1975 and by the American Board of Psychiatry and Neurology in 1977. He went on to establish one of the most clinically active Muscular Dystrophy Association clinics in the tri-state area and developed a national reputation in the study and treatment of autoimmune neuromuscular diseases, motor neuron diseases and muscular dystrophy. In 1991, he was appointed chair of neurology at The Long Island College Hospital while continuing to serve as associate professor of clinical neurology and vice chair of the Department of Neurology at the SUNY Health Science Center at Brooklyn. He was honored for his dedication to the clinical care of patients by being named the first recipient of the Muscular Dystrophy Association's Ade T. Milhorat Humanitarian Award in 1998. He is listed in Who's Who in America, Who's Who In Science and Engineering, New York magazine's "Best Doctors in New York" and Castle Connolly's Best Doctors In America.

After an increasingly close collaboration with Dr. Thomas H. Milhorat throughout the 1990s, his interests expanded to include the diverse and subtle neurological symptoms plaguing Chiari and syringomyelia patients. In 2003, he joined the Chiari Institute as its Medical Director. Dr. Kula is recognized as a Fellow in the American Academy of Neurology and sits on the physician advisory panels of The American Syringomyelia Alliance Project, the Muscular Dystrophy Association, the Neuropathy Association, the National Fibromyalgia Association and the Chronic Fatigue and Immune Dysfunction Syndrome Association. He has been a funded investigator with grants supported by the Muscular Dystrophy Association and numerous pharmaceutical groups.

The Art of Fundraising

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host of other activities to create a unique and successful a-thon. Take into consideration potential volunteers, donors and those who will help with the event and promote it throughout your community—an easy and fun way to raise funds without a lot of expense or major planning.

Raffles and Silent Auctions: Usually held during a dinner event, these types of fundraisers can be held virtually at any time, any place. Raffles can be coordinated through local retail locations with a photo of what is being raffled. Silent auctions can be held at offices, during a golf outing—use your imagination.

Community Garage and Mall Sales Events: Volunteers and donors provide gently used secondhand items to sell. Rent table space for individuals and possibly other organizations for a fee such as \$25-50 per 8-foot table. With the entire community involved you can generate tremendous traffic since everyone loves a bargain and large-scale sales events are generally well attended. Ask your local airport, fairgrounds, banquet facilities, or other large venue to donate space for a day or provide the space at a reduced rate. If you can interest a larger venue, consider teaming up with 4 or 5 other non-profits to split the profits on the rental tables and keep the sales from your own booths.

Holiday Events

Tree of Life/Ornament Sales/Lighted Displays: Decorate your home, your storefront or office building, place trees in front of your building or at locations around your community. Sell paper ornaments or each “light” on display in honor, memory or celebration of a special person in your community. At indoor tree displays, it is easy to have paper ornaments available for sale. Simply print full color business cards with a holiday theme, punch holes in them, insert a gold or high quality yarn or string and sell to hang on the trees on display. Ornaments can easily sell for \$1 - \$5 depending on your community. You’ll have a great holiday fundraiser with little effort! Get your kids involved and try this at their school. If you are a teacher, maybe the principal will allow you to get the whole school involved.

Sell a Product

Bracelets, Greeting Cards, Bookmarks, etc: As mentioned earlier, purchase ASAP products and sell them easily at double, triple or even more of their original cost. A community fundraiser can be done by teaming up with local merchants and retail stores (even try selling to the stores at wholesale prices and let them set the retail price) or team up with a local school and have the children design and sell them during the holidays with a portion of the profits also going to the school. The more local you can make the items the better they will sell.

Golf Outing/Tournament

Golf events are always fun and people like to play when a good cause is involved. Form your own local golf committee to help identify vendors that will contribute sponsorship money for the event. You want to work with a highly rated course in your area. This will give you instant credibility with the golf community, sponsors, and guest pros who attend.

Most of All, Be Creative

The best local fundraisers are unique and not copied from other organizations. Tap into the creativity of your friends/volunteers and come up with unique ideas that highlight their talents. Maybe you have friends/volunteers who are singers or have another talent. Holding a local “talent” show would be the ideal fundraiser. When your event is done, consider hosting a recognition event and keep them in the loop for a future/repeat fundraising event.

With your help promoting your local group and ASAP through events like those listed above, it not only helps with fundraising and public education, it boosts morale and attracts volunteers!

If you want more information about putting on a local fundraiser to benefit ASAP, please contact: Patrice Schaublin at Patrice_Schaublin@ASAP.org

Please let us know if you plan on doing an event so that we can help promote it. Remember, we are all in this together!

Sometime my cross is hard to bear
for there is darkness everywhere,
and troubles pile around my door
like autumn leaves forevermore.

The morning light seems far away,
like I am stuck in yesterday.
My heart is beating like a drum.
I try to pray, but words won't come.

But then the sun begins to rise
and Hope is born within my eyes.
A rainbow forms among my tears
my faith is stronger than my fears!

GMAN

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

Dorothy Culling

Sondra Cole

Pam Holmes

Sondra Cole

John Curiel

Pat Skinner

Judy Hunt

Guy & Marlene Petersen

Joe Svobodny

Janice Ruggles

Brad Laventure

Roy Spring

Mark Fornof

Howard & Maggie Fornof

Lynda Brown

Kristi Gersch

Ryan Brown

Dawn Day

Danielle

Lee Holmes

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Lucille Chavous

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Maria Hamm

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Mr. & Mrs. Bill Piercy

Tim & Barbara Sutherland

Frank Ress

Christopher & Meryl Lewis

Heidi Diven

Arny & Nancy Manseth

Blair Hagelgans

C Drew Brown

In Honor of

Donor

Lee Miller

Andrew Cimmino

Ann & Don Elliott

Holly Patterson

Melbourne Lodge #143

Stuart Patterson

Emily Teasley

Sue Teasley

Robert & Susan Lacey

Michael Sanchez

Ernesto Sanchez

Fred Kemp III

Richard Schulz

Cherith Altizer

James & Jane Ragland

Stephen Crow

Skip Rhodes

The Kelly Family Kids

Mr. Bert Cohen

Maverick Capital Fndtn

Selina Fong

Wendy Law

Candace & Stan Morse

Karen Russell

Sophie Varelmann

Leigh Johnson

Katelyn Jelley

Iole Moirano

SM/CM Children

Helen Marshall

Dr. Ulrich Batzdorf

Margot Vinnemeir

Anthony Cavuoto

Ennio & Valerie Cavuoto

Cash & Krista

Diane Heisler

Guy & Marlene Petersen

Doug & Martha Leerssen

Sean McCarthy

Melinda McCarthy

In Honor of

Donor

Barbara Gaechter

Susan Pommerenke

DeeAnn Solorzano

Dave & Hillary Gross

Cathy Belluardo

Bonnie Petrus

Sue Freund

George McKulla

Jeff, Debbie & Hannah

Weinstein

Sandy Egizi

Sue Canavan

Karen Billings

Brady Coulson

Joy Hilliker

John Elliott

Robert & Penny Elliott

Keesha Turner

Vicki Sulfaro

Charles & Helen Johnson

Steven Johnson



In Memory of

Donor

Wilbur C DuBois

Robert DuBois

Dylan Thomas

Greg Boggs

Bernie Miller

Ann & Don Elliott

Mary Virginia Brown

Sondra Cole

Marcy Speer, PhD

Routzon Family Fndtn

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Marion Doerr

Jan Halverson

Guy & Marlene Petersen

James Andrew Haas

Amy Haas

Mr. S. Prentiss Cherry

Susan McLane

John Gilroy, M.D. 1925-2008

Dr. John Gilroy was born in Newcastle-Upon-Tyne, a coal mining and ship building city located in England's industrial Northeast. His work ethic was evident in his youth when he distinguished himself in academics and athletics.

Upon graduating from medical school at the top of his class, he served in The Royal Navy and later the RAF. In addition, he served for ten years in the Army Reserve in the United States.

He began his remarkable medical career in this country more than 50 years ago as a resident in Neurology at both Detroit Memorial and Detroit Receiving Hospitals. He rose quickly through the ranks and became the Chief of Neurology at Wayne State University and Harper Hospital.

He later became Chief of Neurology at Beaumont Hospital, Royal Oak, Michigan. His vision and dedication led to the creation of the Neuroscience Center at Beaumont, a state of the art teaching and care facility.

His passion was teaching and mentoring medical students and young physicians. He wrote a number of books including Basic Neurology, which is still the most widely read medical reference book on Neurology in the world. It was translated into a number of languages. In 1973 he took a six month sabbatical from the hospital to volunteer for CARE in Indonesia.

Dr. Gilroy was revered by his patients and admired and respected by his colleagues. He passed away on November 13, 2008.

[Editor's Note: Dr. Gilroy was a Chiari specialist.]

You can honor a loved one or a friend through a gift to ASAP. An acknowledgement card will be sent in your name to the person honored or the family of a deceased friend or loved one for a donation of \$5 or more. When making a gift, please send your name and address as well as the name and address of the person or family to whom the card should be sent. Remember to include the name of the individual you wish to honor or remember.

Presidential Proclamation



ASAP CEO Richard T Hellner and Board member Patrice Schaublin represented the American Syringomyelia Alliance Project at a reception to honor Thomas H Milhorat, MD, on December 17. ASAP volunteer Lisa Battaglia petitioned for a Presidential Proclamation acknowledging the efforts of Dr. Milhorat in the advancement and treatment of syringomyelia and Chiari malformation. The ASAP-sponsored reception was attended by approximately 40 people including Dr. Milhorat's family, professional colleagues and community members.

Save Your Canceled Postage Stamps

ASAP members began collecting canceled postage stamps as a fundraiser during the early 90s. They have enlisted the aid of local businesses, churches, social clubs, family and friends. The number of stamps donated has dramatically increased over the years.

This fundraising project is a favorite of many ASAP members. Although commemorative stamps such as the 'State' series bring in more money, the everyday 'flag' stamps are also of value. Since 1999, we have raised over \$6,000 through this project. So the next time you start to toss that envelope, take a few minutes to help ASAP.

Cut stamp from envelope leaving a 1/4 inch border. They must be in good condition; damaged stamps are not usable.

Please send stamps to:

Maynard Guss
9593 NW 26th Place
Sunrise FL 33322-2738



New Resource: Chiari Malformation and Syringomyelia Handbook

This excellent new resource explains the neurological disorders, Chiari malformation (CM) and syringomyelia (SM) for the newly diagnosed, family members, caregivers, and medical professionals who want to know more about these potentially devastating disorders. Each chapter is written by a medical specialist and it is edited by Ulrich Batzdorf, MD, Professor of Neurosurgery and Director of Spine Surgery David Geffen School of Medicine at UCLA. The handbook addresses the complex issues faced by the hundreds of thousands of people with CM/SM. It provides reliable, current information on symptoms, diagnosis, genetic implications, surgery, symptom management and chronic pain relief. It also includes a medical glossary and resource list.

Dedicated to Marcy Speer, PhD, the guide is made available through a grant by the Lita Annenberg Hazen Foundation and can be downloaded free of charge at **www.ASAP.org**. For anyone who cannot download the file, a copy can be obtained from the ASAP office. Send your request to PO Box 1586, Longview TX 75606 A donation of \$2.00 to cover the cost of shipping would be appreciated.

Free Ways to Help American Syringomyelia Alliance Project, Inc. Raise Much-Needed Funds

Every time you shop at any of 700+ online stores in the iGive network, a portion of the money you spend benefits American Syringomyelia Alliance Project, Inc. It's a free service, and you'll never pay more when you reach a store through iGive. In fact, smart shoppers will enjoy iGive's repository of coupons, free shipping deals, and sales. To get started, just create your free iGive account. And when you search the web, do it through **iSearchiGive.com** where each search means a penny (or more!) for our cause!

Start iGiving at: **www.iGive.com/SM** and **www.iSearchiGive.com/SM**



The American Syringomyelia 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 articles, letters to the editor, etc. are encouraged. The deadlines for these submissions are the 1st of February, April, June, August, October and December. The editor reserves the right to edit any article in order to accommodate space. Please send newsletter suggestions to: Patricia_Maxwell@ASAP.org or ASAP, PO Box 1586, Longview TX 75606

Patricia Maxwell Editor, *ASAP Connections*

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