

Chiari & Syringomyelia News

Delivering The Latest Research, News, and Information

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Foundation News

Save The Dates:

Conquer Chiari Walk Across America 2010: September, 18th 2010

3rd Annual Pediatric Gala: October 15th, 2010

Inside this issue:

<i>Editorial: Reality Check</i>	2
<i>Ray's Corner: Chiari & Pregnancy</i>	7
<i>Meet The Board: Dave Lee, Vice President</i>	10
<i>Glossary</i>	12

Happy Holidays!

Evaluating Quality Of Life With Syringomyelia

Syringomyelia, which often involves a slow, progressive deterioration can have a profound impact on patients. In a recent study, published in the *Journal of Clinical Neuroscience*, a group of German scientists tried to quantify just how syringomyelia impacts quality of life. In addition to the inherent benefit of measuring the quality of life impact, the research team hoped to identify sub-groups of SM patients which might then have implications for treatment.

While a syrinx caused by a Chiari malformation lends itself to a surgical treatment focused on decompressing the area around the cerebellar tonsils, syringes can also be a result of spinal cord injury, tumors, infection, and in some cases for no discernable reason. The treatment approach for these types of cases is not nearly as straightforward or clear. Options include conservatively trying to

manage symptoms, locally decompressing around the syrinx in order to restore local CSF flow, and even draining the syrinx directly with a shunt. Unfortunately, none of these options is a clear winner, and even with Chiari related syringomyelia, many patients will have residual symptoms, such as pain and loss of sensation, associated with a syrinx. [Editor's Note: When I had surgery in 1999, the general description of surgery if there was a syrinx, was that it would hopefully stop the progression of symptoms, not that the syrinx related symptoms would improve. Now, research has shown that some syrinx related symptoms can improve with Chiari decompression surgery, but that others are less likely to.]

The research involved a large group of 142 syringomyelia patients seen over the course of a year at the University of Tubingen.

See Page 3

Endoscope Used To Minimize Surgery In Children

A report from a pediatric neurosurgeon at the Cleveland Clinic (Di) shows promise for a less invasive type of Chiari surgery for children. While there is an ongoing debate in the medical community regarding minimally invasive surgery - meaning, the dura is not opened, the focus of this publication is using an endoscope for visualization, which allows for a less intrusive surgical

approach.

An endoscope is a thin flexible tube which can be inserted into the body through a small opening. The endoscope contains a lens and light which allows the surgeon to view internal structures on a monitor and guide the surgery (Figure 1).

See Page 5

Editorial: Reality Check

I hope everyone enjoyed their Thanksgiving holiday and were able to forget about Chiari for awhile. While I certainly did enjoy myself, in the back of my mind something kept nagging at me the whole time. Specifically, I knew that when I got back to work, I would have to publish a newsletter, this one, with very little content. I have been working on Chiari & Syringomyelia News since 2003, and unfortunately, while progress has been made on many fronts in the battle against Chiari, there are still long stretches of time where there is very little published research of interest.

The past few months have been one of those times. This newsletter contains only two research updates. Fortunately, they are both pretty interesting and represent good work in the medical/research community, but there is no getting around the fact that in terms of quantity, published Chiari research lags behind other diseases that affect about the same number of people. I've discussed before possible reasons for this (neurosurgeons are too busy to do research, no pharmaceutical solution) and won't belabor the point, but it is an area that we need to continue working on.

On the positive side, as Conquer Chiari continues to grow - thanks to your hard work - we will be able to have more and more of a direct impact on the research community. Based on the success of this year's fundraisers, it is our intent to fund \$250,000 worth of research grants in 2010. Of course, this is on top of the studies we funded earlier this year which will still be ongoing. As we are able to focus more funds on research, we will in turn be able to increase the pace of research publications. In addition, we have begun organizing our next professional research conference which will be held in November, 2010.

In fact, as I think forward to the projects we will be funding over the next 2-3 years, I feel good about the progress we are making on our research agenda. Although the road is long, we are definitely underway. If you are not familiar with the Conquer Chiari Research Agenda, here it is:

Goal #1: Reduce the average time to an accurate diagnosis to less than 2 years from time of first symptoms.

- Develop a standard, simple, objective definition and test of symptomatic Chiari
- Enable the introduction of new technologies, such as inexpensive, portable imaging, which will reduce the barriers to diagnosis

Goal #2: Develop an effective, widely adopted, and minimally traumatic standard of care.

- Design, and encourage the adoption of, a standard outcome measure, such that the results from different studies can be compared and combined
- Establish whether the surgical variations that currently exist have a significant effect on long-term patient outcomes, and further develop a standardized surgical approach
- Encourage the development of minimally invasive surgical techniques
- Pursue non-surgical treatment approaches which don't just address symptoms, but are targeted at the core problem(s)

Goal #3: Minimize the impact that Chiari has on the quality of life of patients.

- Develop, and encourage the adoption of, a Chiari Impact Measure, which takes into account patient focused issues such as career, family, economics, recreation, and socialization
- Understand, and develop treatments for, the neuropsychological effects of Chiari, including both cognitive and emotional manifestations
- Develop widely accepted protocols for physical, occupational, and other types of therapies designed to maximize functional capabilities
- Enable the development of innovative technologies and treatments targeted at the neuropathic pain and loss of function associated with Chiari

Goal #4: Understand the pathophysiology, natural history, and epidemiological characteristics of Chiari.

- Establish, with reasonable accuracy, the incidence and prevalence of Chiari and Chiari related syringomyelia
- Characterize, and quantify, the Chiari experience, such as average age of diagnosis, time to diagnosis, number of doctors seen, major symptoms, etc.
- Develop a sound theoretical model for the pathophysiology of Chiari, which explains how symptoms develop, and will enable predictions about who needs surgery, who will develop syringomyelia, etc.
- Identify and characterize the genetic basis of Chiari

-- *Rick Labuda*

Evaluating Quality Of Life With Syringomyelia

The patient group was comprised of 88 women and 54 men, and not surprisingly, the syrinxes were due to a variety of causes. Specifically, 26% of the group had Chiari related syrinxes, 25% were associated with a traumatic spinal cord injury, and in another 25%, the underlying cause could not be determined (Table 1). Common symptoms for the group included pain (68%), numbness (62%), ataxia (43%), and paresis (31%) (Table 2). Interestingly, the group was split almost evenly in terms of treatment with 75 patients having undergone some type of surgery, and 67 patients pursuing a conservative treatment plan.

In order to assess the impact syringomyelia had had on the group, the researchers employed widely used, validated measure, the SF-36. The SF-36 is a quality of life survey which can be used to generate both a physical score and a mental score. In addition, the researchers gave the participants a survey called the Syringomyelia Disability Index (SDI), which asks questions about pain level, physical function, and routine activities, and generates a disability score between 0%-100%.

Overall the average SF-36 physical score (PCS) for the group was 33.2 and the mental score (MCS) was 45. These are both well below the established norms in Germany of 50.2 and 51.5 respectively. In fact the physical score of the SM group was lower than the average of people who suffer from chronic back problems, and the mental score was comparable to what has been recorded for people with chronic heart conditions and cancer. The average score on the SDI was 64%, which is very high.

Interestingly, the researchers found no difference in the scores between the men and women of the SM group. Similarly, and somewhat distressing, they also found no real difference in scores between those who had surgery and those who didn't. This would seem to indicate that once a syrinx causes damage to the nervous system it can be very difficult to get that function back (although it is important to note that there are billions of dollars being spent on nerve regeneration research). Of course this does not mean that surgery for those patients wasn't necessary, as the surgical intervention may have prevented further damage. Also of interest is the fact that there was no difference in the quality of life scores based on the underlying pathology, so it appears that a syrinx is a syrinx no matter how or why it forms.

The researchers did find that disease duration was correlated with lower physical scores, but not

mental scores. This implies that syringomyelia can progress over time, but also that at least some patients learn to accept and adapt to their situation. One factor that did negatively impact the mental score was not knowing the cause of syringomyelia. In other words, people for whom there was no discernible cause for the SM had significantly lower MCS scores than those who had a readily identifiable cause, such as Chiari.

Finally, it was clear that SM has a big impact on patients' ability to work. In this study group, only 29% were still working at their original jobs. Another 12% had changed careers because of SM, and more than a third were forced to quit or retire early. Although the researchers did end up identifying sub-groups of patients based on their physical and mental scores, it is not clear that any strong conclusions could be drawn from having done this.

Well designed quality of life studies such as this one are a rarity for Chiari and syringomyelia, but the results clearly show that more work in this area is called for.

-- Rick Labuda

Source: Evaluation of quality of life parameters in patients who have syringomyelia. Sixt C, Riether F, Will BE, Tatagiba MS, Roser F. J Clin Neurosci. 2009 Oct 7. [Epub ahead of print

See Page 4

Evaluating Quality Of Life With Syringomyelia

**Table 1: Underlying Pathology of SM Patients
(142 Total)**

Pathology	%
Chiari Malformation	26%
Spinal Cord Injury	25%
Tumors	16%
Other	9%
Unknown	24%

ataxia - uncoordinated, staggered walking

SF-36 - widely used, validated quality of life scale, consists of surveys and produces rating on a number of subscales

paresis - partial paralysis

vertigo - dizziness

**Table 2: Common Symptoms Among SM
Patients (142 Total)**

Symptom	%
Pain	68%
Numbness	62%
Ataxia	43%
Paresis	31%
Headache	28%
Vertigo	26%

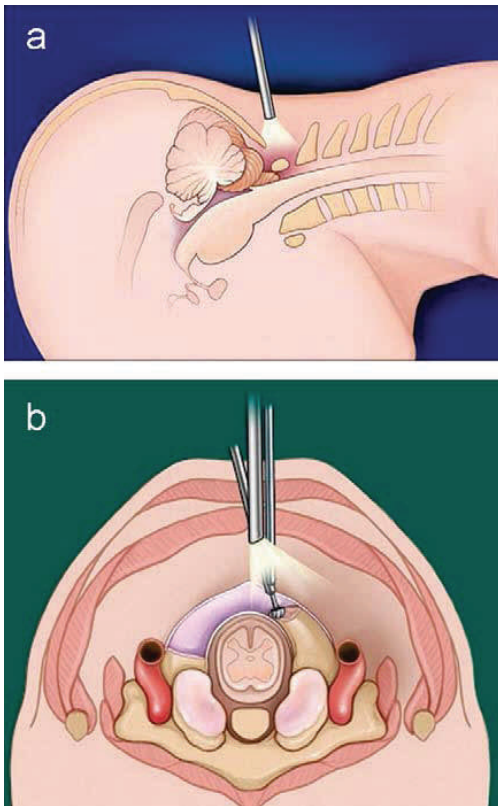
Key Points

1. Syringomyelia has a major impact on patients
2. German study looked at the quality of life of 142 syringomyelia patients
3. SM was due to Chiari, SCI, tumors, and for unknown reasons
4. Found that the physical QoL was lower than reported by chronic back pain patients
5. The mental QoL was on par with cancer patients
6. Found no difference between men and women; and no difference between those who had had surgery and those who didn't
7. Did find that duration of symptoms was related to lower physical scores
8. Also found that SM has a big impact on a patient's ability to work

Endoscope Used To Minimize Surgery In Children

Endoscopes have been used for various procedures for some time now, but are not commonly used for Chiari surgery. Instead, larger opening are made and then many surgeons use a microscope for work near the spinal cord and brainstem. Thus, in theory, using an endoscope should allow for a less invasive surgery, which in turn would lead to less trauma and a quicker recovery.

Figure 1: How Endoscope Is Used In Chiari Surgery



In this publication, Dr. Di reports on his experience with 26 pediatric, Chiari patients. The group was comprised of 16 boys and 10 girls, ranging in age from 18 months to 16 years. As to be expected, headache and neck pain were the most common presenting symptoms (Table 1), followed by weakness and numbness in the extremities, swallowing and gastrointestinal issues, and developmental delays.

MRIs showed that each child clearly had a Chiari malformation and were candidates for surgery. In addition, 5 children also had syrinxes, 4 had hydrocephalus, and 1 had PTC. The children underwent a similar surgical procedure which involved a

2cm incision, a craniectomy, and a C1 laminectomy.

There were no CSF related complications, however one child did develop meningitis which was effectively treated. With no complications, most of the children only spent 1 or 2 nights at the hospital. In terms of outcome, the surgeon reports that 18 of the group had an excellent outcome and an additional 6 were improved (Table 2). Two patients did not improve, and one girl required an additional surgery after suffering a neck trauma at a later time.

While the success and complication rates reported are very good, it is unfortunate that this report did not compare the endoscopic surgery with a more traditional approach. In other words, does it really result in less pain for the children and shorter hospital stays? It is also important to note that a clear definition of the different outcome levels was not provided, so the difference between excellent and improved is not known.

Until this surgical technique is directly compared to others, it is very difficult to evaluate its merits and potential drawbacks. However, the author does note one drawback, namely that it takes a good bit of practice to be able to use the endoscope effectively in this way.

-- Rick Labuda

Source: Endoscopic suboccipital decompression on pediatric Chiari type I. Di X. *Minim Invasive Neurosurg.* 2009 Jun;52(3):119-25.

See Page 6

Endoscope Used To Minimize Surgery In Children

Table 1: Presenting Symptoms of 26 Pediatric Chiari Patients

Symptom	Number With
Headache, neck pain	11
Weakness, numbness in	8
Swallowing problems,	7
Developmental delays	6
Ataxia	5
Sleep apnea	2

Table 2: Surgical Outcome of 26 Pediatric Chiari Patients

Outcome	Number
Excellent	18
Improved	6
No Change	2

Notes: Outcome levels were not clearly defined in publication

ataxia - uncoordinated, staggered walking

craniectomy - surgical procedure where part of the skull, or cranium, is removed

C1 - refers to the first cervical vertebra

dura - thick, outer covering of the brain and spine

endoscope - surgical instrument comprised of a flexible tube, lens, and light which allows for the visualization of internal structures

hydrocephalus - condition involving the abnormal accumulation of CSF in the brain

PTC - pseudo tumor cerebri; condition where the pressure of CSF in the brain is abnormally high

sleep apnea - condition where a person repeatedly stops breathing for a short period of time during sleep

Key Points

1. An endoscope is an instrument which allows surgeon to visualize the surgical field through a small incision
2. Using an endoscope should allow for a less invasive surgery, meaning less trauma for the child and a quicker recovery
3. Surgeon from Cleveland Clinic reports on his experience using an endoscope for Chiari surgery in 26 pediatric patients
4. There were no CSF related complications, however one child developed meningitis
5. Overall outcomes were very good with 24 out of 26 patients showing an improvement in symptoms
6. However, the technique was not directly compared with a more traditional approach for factors such as post-op pain, medication use, and length of hospital stay

Ray's Corner: Chiari & Pregnancy

[Ed. Note: The opinions expressed below are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. The author is not a medical doctor and does not give medical advice. Anyone with a medical problem should seek professional medical advice]

Scientists and research physicians are always looking for projects where maximum learning can be rendered from minimal investments. We call these project low hanging fruit. Every year since 2004 usually in the January edition, Conquer Chiari publishes a review article summarizing research progress. While overall progress is slow because of limited research funds, some interesting findings have emerged but for the most part the message sounds like a broken record for those of you old enough to have experienced listening to a broken record. Most of the studies published are individual case studies which aren't particularly helpful for understanding the general condition. The remainder is mostly split between studies reporting on new surgical techniques or comparing surgical techniques along with outcome results and studies looking for new objective measures of diagnosing Chiari primarily using MRI. Surgical and outcome studies have produced results all over the map and have proved difficult to compare because of the lack of standard and valid method for evaluating outcome. And, finding a way to objectively measure the disease in a reliable manner has proved elusive even with the most sophisticated imaging technologies. I remain confident however that these important problems will be resolved in the near future particularly if agencies like the National Institutes of Health increase funding for Chiari research to a fair level.

But, the topic of this column is not so much the need for better treatment outcome and diagnostic

measurement research as it is to point out one particular area of needed research that has been on my mind for several years and that is Chiari and child birth. The incidence of Chiari in women may be as much as three-fold higher than it is in men¹ as derived from a large landmark prospective study. Also, with increased awareness and better access to MRI, the mean age of symptomatic onset as reported in the same study is about 24 years of age. As a result, many women of child bearing age are finding out on a daily basis that they have Chiari. Many of these women are thinking about starting a family. Some are in a situation where they are already pregnant. In both scenarios, questions abound. Is it safe for me to have a baby? What about my safety? Will labor make my symptoms worse? What are the possible complications? If my Chiari gets worse, how will I manage to care for my baby? These are just a few questions.

It is well known that the strain involved during labor may increase intra-cranial pressure. And this simple fact gives rise to concern when pressure on the hind brain structures is already compromised in patients with Chiari. I have been involved in the Chiari community now for about 12 years. During this time, I have talked with numerous women and have read numerous posts on-line by women who have discussed their problems and fears with child birth. A large number have claimed that labor triggered their symptoms and that prior to becoming pregnant they were asymptomatic. Others claim that child birth significantly worsened their symptoms.

With this in mind, I recently did a search of the medical literature to see what has been reported with regard to Chiari and pregnancy/child birth.

See Page 8

Ray D'Alonzo, Ph.D., is a visiting professor in the Chemistry Department of the University of Massachusetts Amherst and a retired R&D Manager of Procter & Gamble where he worked for over 31 years. He has led research programs in bone metabolism, infectious disease, respiratory disease, arthritis, and nutrition and has published scientific papers on a wide variety of topics from the chemical composition of fats and oils to the pharmacoeconomics of osteoporosis. Dr. D'Alonzo is the recipient of the Chancellor's Medal from the University of Massachusetts, Amherst, in part, for his contributions to the development of new pharmaceutical agents. As both a patient and scientist, he has made a personal effort to increase the awareness of Chiari in the health care sector and to assist others afflicted with the syndrome. He has published the story of his personal struggle with Chiari in a book, [Contents Under Pressure](#), with 100% of royalties going towards Chiari education, awareness, and research programs.

Ray's Corner: Chiari & Pregnancy

In setting out to do this search, I anticipated that I would not find many papers but that within those I did, I would see that Chiari did indeed result in complications during pregnancy and the postpartum period. A quick search revealed five publications²⁻⁶, about the number I expected. Four of these papers were case studies. One paper⁴ was a small study involving seven women. I was shocked after reading the abstracts that not a single complication was reported. In fact, in all cases, the Chiari symptoms of the mothers either resolved or returned to pre-pregnant levels postpartum.

Given the large number of women who have testified otherwise, how can this be? Without getting technical, the likely primary explanation for this apparent discrepancy is that the number of women studied in these publications is small. This deficiency is actually called out in the publication by Mueller and Oro⁴. In this paper, the investigators employed a very simple study design where the seven women participating were asked to complete questionnaires pertaining to their symptoms during pregnancy, labor and postpartum. This study really amounts to a pilot study and needs to be repeated using a much larger number of women. In order to do this a study with multiple sites would need to be designed so that a larger number of patients can be recruited to participate in a reasonable period of time. A multi-center study of simple design could be very cost effective and would provide some real insight as to the real incidence of complications associated with child birth as well as the nature of the complications. The study could also be designed to screen women of child bearing age by MRI for possible inclusion in the study who themselves are daughters of a parent with Chiari. This might result in more quickly completing study enrollment as well as provide an idea of the risk of passing along the condition assuming it is genetic.

Sticking my neck out on a limb here a little, let me make an editorial remark which is that the world of Chiari research is dominated by men. As such, they seem to be overly focused with playing with their high tech toys to measure things like intra-cranial flow, pressure, structure dimensions, and compliance or with advancing surgical techniques involving the shape of dural grafts and grafting materials. It's the snakes and snails and puppy dog tails in us that gives us this kind of driven focus and dare I say insensitivity to other

needs. We need to listen more to sugar and spice and everything nice a bit more. If we did, I guarantee that there would be more than four case studies and one pilot study in the literature and we could really put a dent in this awful disease. Chiari and complications with child birth looks very much to me like low hanging fruit ripe for picking.

Seasonal Postscript: *I would like to clarify for readers that the only proven effective measures for preventing the spread of the common cold and flu, both H1N1 and seasonal, are vaccination, isolation, and respirators (not masks). The spread of these infectious viruses is largely achieved by airborne transmission. Their spread by hand contact is very secondary. There are no clinical data showing that the wearing of dust and surgical masks can prevent the spread of these viruses. Coughing and sneezing into ones elbow has little effect on lessening their dispersion into the air. The washing of hands is effective but only against the relatively small percentage of cases that are spread in this manner. Viruses are extremely small, smaller than most airborne dust particles. If you have ever watched the sunshine beaming through a window, you cannot help but observe all the tiny dust particles that seem to float endlessly in the air. This is exactly what viruses do. When an infected person coughs, sneezes or even breaths they fill the air around them with millions of virus particles. Coughing into ones elbow does little to trap them. The same is true for dust and surgical masks. These tiniest of microbes pass right through them or exit right along with the air around the edges of the mask which are far from air tight. It may be polite to cough in your elbow but it is totally ineffective. The most effective measure to prevent their spread is to dilute their airborne concentration by improving ventilation. If you are in an enclosed room where people are coughing, try to open a window or leave the room. Of course, people with the cold or flu should remain home and work if necessary by remote computer access if possible. I like to provide such information based on data as opposed to medical mythology this time of year because the last thing a Chiari patient needs is the flu or a nasty cold. Stay healthy my friends!*

See Page 9

Ray's Corner: Chiari's Many Faces of Sleep Disturbances

¹Chiari I malformation redefined: clinical and radiographic findings for 364 symptomatic patients, Milhorat TH, Chou MW, Trinidad EM, Kula RW, Mandell M, Wolpert C, Speer MC, Neurosurgery, 1999 May;44(5):1005-17.

²Neuraxial analgesia during labor in a patient with Arnold-Chiari type I malformation and syringomyelia, López R, Nazar C, Sandoval P, Guerrero I, Mellado P, Lacassie HJ., Rev Esp Anesthesiol Reanim. 2007 May;54(5):317-21.

³Uneventful epidural labor analgesia and vaginal delivery in a parturient with Arnold-Chiari malformation type I and sickle cell disease, Newhouse BJ, Kuczkowski KM., Arch Gynecol Obstet. 2007 Apr;275(4):311-3.

⁴Chiari I malformation with or without syringomyelia and pregnancy: case studies and review of the literature, Mueller DM, Oro' J., Am J Perinatol. 2005 Feb;22(2):67-70.

⁵Anaesthesia for caesarean section in a patient with syringomyelia and Arnold-Chiari type I malformation, Agustí M, Adàlia R, Fernández C, Gomar C., Int J Obstet Anesth. 2004 Apr;13(2):114-6.

⁶Maternal Arnold-Chiari type I malformation and syringomyelia: a labor management dilemma, Parker JD, Broberg JC, Napolitano PG., Am J Perinatol. 2002 Nov;19(8):445-50

-- Ray D'Alonzo

*** If you would like to share your comments, thoughts, or ideas with Ray, please send them to dalonzo.rp@gmail.com. Due to the volume and nature of email received, individual responses are not possible. ***

Meet The Board: Dave Lee, Vice President

As part of our ongoing effort to be as open as we possibly can about how the Foundation operates, we have decided to profile our Board of Directors in the next few newsletter issues.

It may come as a surprise to some of you that even though I [Rick Labuda] founded Conquer Chiari and as Executive Director am responsible for daily operations, I am not on the Board of Directors. When I formed the Foundation, I was advised that it would be more professional to not be part of the board, thereby ensuring objective oversight. It may also surprise some of you that there are no patients or parents of Chiari kids on the board either; rather, our small, active board is comprised of 3 experienced, business professionals and a medical professional. Again, this enables an objective evaluation of programs and priorities without personal biases and agendas. I believe that our approach in designing the Foundation's oversight has, over time, proven to be a good decision. Our Board of Directors is a tremendous asset and has allowed us to maintain a high level of professionalism in aspects of our operations.

This month, meet the newest member of our Board, Dave Lee, Vice President...

What is your professional background?

Like Rich Kushner, my professional background is heavily technology-focused. I have an accounting degree from Boston University, and have started my professional career in accounting, but even during that time, much of my time was spent automating information systems. I subsequently worked primarily for small businesses, including a non-profit, leveraging the emerging internet communication infrastructure as a way to get information into the hands of the intended recipients. In 2000 I joined Marconi (which subsequently was acquired by Ericsson) and moved to Pittsburgh. I recently joined DynaVox Mayer-Johnson, a company focused on using technology to allow those who cannot speak to have a voice through speech generating software. I am product manager for several of their appliances and see real opportunity to make a difference in how people think about these devices.

What skills and experience do you feel you bring to Conquer Chiari?

I've known Rick Labuda for about a decade, and I think it's fair to say that Rick's engaging style is a big part of why I'm involved with Conquer Chiari. Even before I joined the board of Conquer Chiari I spent a fair amount of time thinking about, and discussing, how to use technology to further the goals of his organization. CC has two main charters; first, to educate doctors, patients and families on Chiari malformations, their causes, and current protocols for treatment. The second is to fund research to improve understanding of both the causes of the disease and how it is treated. There was a time when a printed newsletter or magazine was the best way for an organization to reach constituents, but the cost and limited reach have been replaced with the web and the massive reach that it represents. So reaching the first goal of getting information into the hands of those that need it is magnified by the reach that electronic publishing represents. The second goal, funding continuing research, relies less on information technology, and Rick, Diane Mueller, another board member, and our Scientific Advisors play a much more prominent role.

What technologies are on the horizon that you think Conquer Chiari may be able to utilize?

From my perspective, using social networks like Facebook in combination of a patient registry presents a good opportunity to build a unique tool for both patients and researchers that doesn't really exist for any patient advocacy organization today. The ability to link people socially in a positive way can really help a person who feels isolated by a new diagnosis to understand quickly that there is a great support network out there.

What do you think Conquer Chiari does well?

Conquer Chiari, to me, is a great organization because it is entirely focused on just a few crucial goals: providing information to patients and their families, raising both public and medical community awareness, and sponsoring key research. I think that CC does a good job of keeping that focus without allowing other potential distractions to defocus the mission. I also recognize that CC has done a fantastic job of raising awareness without the kind of marketing budget that many organizations have.

See Page 11

Meet The Board: Dave Lee, Vice President

In what areas do you think Conquer Chiari needs improvement?

I think most of the answers are along the same key points as the previous question: the biggest areas for improvement are to continue the reach and awareness that CC is generating. We have recently been reaching people outside the U.S. with the information we are providing. It think we need to recognize the reach that we have and find a way to leverage that in a way that improves patient education and care in that larger context.

What do you think Conquer Chiari needs to do in order to take the organization to the next level?

I think that the three things Conquer Chiari needs to do to go to the next level are:

1. Continue to build on the success of the Walk Across America event. There's a real opportunity to expand the number of events on that day as well as increasing the awareness within the communities that are hosting events.
2. Continue to expand successes in Washington DC with legislation and work at NIH
3. Explore whether it makes sense to get involved with a trade or medical society event. I just returned from a conference related to my "day job" and was reminded that driving awareness in that direction could help get companies who make medical equipment to start thinking about what can be done to better detect and treat Chiari.

What role do you think the board in general, and you as Vice President in particular, play in an organization such as this?

Conquer Chiari has a great executive director in Rick Labuda. The role of the board is to help sift through the hundreds of possible things Conquer Chiari could be doing to hopefully find the most impactful ways to direct its resources. The second thing the board does is to pitch in and help on occasion, since Conquer Chiari runs a lean organization. For example, I worked with Rick to help design and launch the Conquer Pediatric Chiari website this past year, and it was very rewarding to see it go live.

You attended the Walk in Pittsburgh, aside from the rain, what did you take away from that experience?

The sense of community within the Pittsburgh Chiari friends and patients sphere is really great. The turnout was fantastic, especially considering the rain and cold. It would have been really easy and actually quite understandable if people just stayed home. It really speaks to the commitment level of the people involved with this organization. As I am answering this question we are well into November and we would've been lucky then to have the kind of weather we're experiencing now. Maybe next year we should schedule it for early November and order up some Indian Summer!

Do you think you could say syringomyelia three times fast if you had to?

Actually, yes! ...but it could help if I was allowed to pronounce it differently.

Glossary: Common Chiari Terms

central canal - very center of the spinal cord, so named because it starts as a hollow tube which closes in most people as they age

cerebellar tonsils - portion of the cerebellum located at the bottom, so named because of their shape

cerebellum - part of the brain located at the bottom of the skull, near the opening to the spinal area; important for muscle control, movement, and balance

cerebrospinal fluid (CSF) - clear liquid in the brain and spinal cord, acts as a shock absorber

cervical - the upper part of the spine; the neck area

Chiari malformation - condition where the cerebellar tonsils are displaced out of the skull area into the spinal area, causing compression of brain tissue and disruption of CSF flow

Chiari II - more severe form of malformation which involves descent of parts of the brainstem and is usually associated with Spina Bifida

cine MRI - type of MRI which can measure CSF flow

compliance - a measure of how much a vessel changes in volume due to a change in pressure; dV/dP ; the inverse of elastance

cranial nerve - one of 12 pairs of nerves that originate in the brain as opposed to the spinal cord

craniocervical junction - the area where the skull and spine meet

cranium - the skull

craniectomy - surgical technique where part of the skull is removed

decompression surgery - general term used for any of several surgical techniques employed to create more space around a Chiari malformation and to relieve compression

dura - tough, outer covering of the brain and spinal cord

dural scoring - surgical technique where a series of cuts are made into the dura, but the dura is not completely opened

duraplasty - surgical technique where the dura is opened and expanded by sewing a patch into it

graft - material, or tissue, surgically implanted into a body part to replace or repair a defect

hydrocephalus - a condition where there is an unusually large amount of CSF in the brain, resulting in swollen ventricles

ICP - intracranial pressure; pressure of the CSF inside the skull

intradural exploration - general term referred to a surgeon finding and removing any scarring or obstructions to CSF flow that exist underneath the dura

laminectomy - surgical technique where part of a vertebra is removed

lumbar - the lower part of the spine

magnetic resonance imaging (MRI) - diagnostic device which uses a strong magnetic field to create images of the body's internal parts

posterior fossa - depression on the inside of the back of the skull, near the base, where the cerebellum is normally situated

syringomyelia (SM) - neurological condition where a fluid filled cyst forms in the spinal cord

syrinx - fluid filled cyst in the spinal cord

thoracic - relating to the middle part of the spine, or chest area

tonsillar herniation - descent of the cerebellar tonsils into the spinal area; often measure in mm

ventricle - a CSF filled space in the brain

vertebra - one of the individual bones of the spinal column



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The C&S Patient Education Foundation is a 501(c)(3) non-profit organization dedicated to improving the experiences and outcomes of Chiari and syringomyelia patients through education, awareness and research. Our goal, quite simply, is to Conquer Chiari.

To support Chiari & Syringomyelia News, and the Conquer Chiari effort, you can make a tax-deductible donation at www.conquerchiari.org. Or send a check, made payable to C&S Patient Education Foundation to:

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