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BOXER IN FULL BLOOM

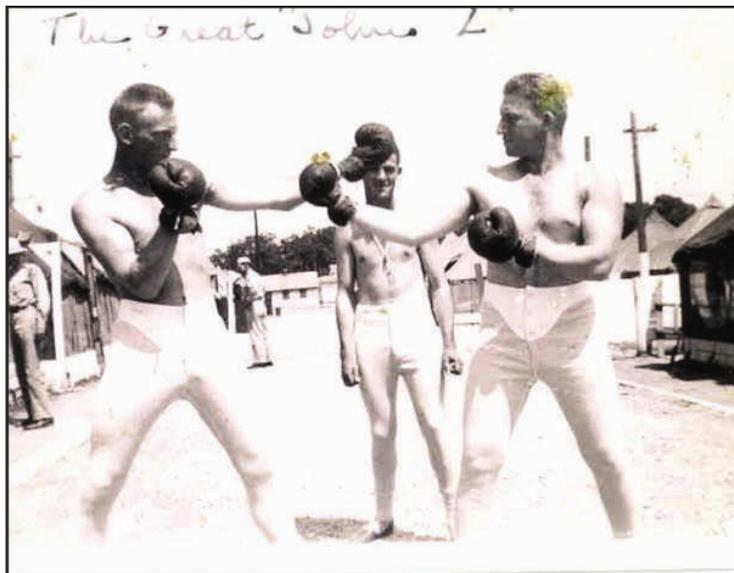
Last summer, while shopping with my 3 year-old son William one Sunday afternoon, my pager beeped, introducing me indirectly to Harry Bloom. Through our processes of diagnosis and healing over the next several months, Mr. Bloom captured not only much of my attention but also my imagination. The call that Sunday was from Dr. David Sidransky, a colleague in the Department of Oncology at Johns Hopkins. Earlier that same day, Dr. Sidransky had been summoned by

Mr. Bloom, a once rugged veteran of Chennault's Flying Tigers, the fabled World War II Air Force unit, now lay unable to get out of bed because of pain that wracked his body. Suspecting a rheumatological problem, Dr. Sidransky called for my help.

Only several weeks before, Mr. Bloom had actively managed his decades-old printing concern:

Harry Bloom Publishing

Every morning Harry had sauntered forth into his beloved Baltimore, the town of his birth. He did so in good-humored defiance of Alice, who worried – often aloud – about his continuing to drive. Carrying samples of his printing work in the trunk of



Harry Bloom (right) sparring for the camera with a fellow "flyboy".

his next-door neighbor, Alice Bloom, to see her husband, Harry. Harry was a robust 84 year-old who, over the span of just one month, had become rapidly disabled by diffuse body pains.

his car, Mr. Bloom greeted his regular customers with an endearing, lopsided grin. To talk with Harry Bloom for only a short time was to be treated to a lesson in the history of Charm City, as

the real Baltimore is known. For those too young to recall the time when well-defined ethnic enclaves dotted the city's map, Harry recalled with a gleam in his eye his youth in East Baltimore's "Corned Beef Row", named for the Jewish delicatessens that once lined Lombard Street.

Perhaps his best stories, though, were about his days in the war. After Pearl Harbor, Harry enlisted in the Air Force at the age of 21, leaving his fiancée Alice Kramer back in Baltimore. Though neither imagined it at the time, Harry and Alice would be separated by the war for four years. After basic training, a trans-Pacific journey on a troop carrier, and a harrowing flight "over the Hump" – the Himalayas – Private Bloom found himself fighting with General Chennault's outfit in China. When not battling the forces of Imperial Japan, Harry and his squadron mates often boxed as a way of passing time and channeling excess energy. A faded black-and-white image (*photo on the front page*) bears the hand-scrawled title "*The Great John L.*", a reference to John L. Sullivan, Heavyweight Champion of the World (1882-1892). Wearing white long johns – regulation Everlast trunks were in short supply in wartime China – Harry is shown preparing to square off against one of his comrades-in-arms. The two fighters are separated by a boyish-looking referee, clad in the same gear. Viewed through the prism of sixty years, the site of these muscular young men in long underwear confronting each other with looks of mock fierceness is amusing. But as Mr. Bloom recalls soberly, the day after the photo was taken, the youthful referee – "*a well-spoken boy; musta been from a nice family...*" – was killed in an air raid. Far from Baltimore, Harry B. was engaged in serious work.

After the war, Harry returned to Baltimore, married Alice, and in short order established a printing business. He moved from the Lombard Street area to Northwest Baltimore in the 1950s, but all of Baltimore from Greektown to Pikesville remained his turf. He knew all of the businesses as they came and left, and had anecdotes to tell about many. He raised two daughters, Leslie and Sandy; made and kept many friends; celebrated the arrival of 6

grandchildren and 2 great-grandchildren; and, in time, began to grow old. Despite cardiac bypass surgery in 1990, at a time when many in his generation were moving to retirement homes or otherwise gone, Harry continued to run his business and embrace the world in a boxer's clinch. Once when he took me to lunch, we faced an interminable



Baltimore's "Corn Beef Row" 1939

Photo courtesy of Attman's Deli (Lombard Street)

wait for a table. As the starting time of the afternoon clinic session was approaching rapidly, I began to peer anxiously at my watch. I then marveled at the style of this octogenarian as he negotiated with waiters, the manager, and chatted up other patrons: bobbing and weaving, always looking for an opening, always wearing a knowing smile. We soon had a table, enjoyed our lunch, and he got me back in time for clinic.

All of these things I was to learn about Mr. Bloom in the weeks that followed Dr. Sidransky's call. But on that Sunday, standing in the parking lot, managing the cell phone in one hand and William and his first baseball glove in the other, I focused on Dr. Sidransky's presentation of Harry's symptoms. Harry had felt great until only one month earlier. Since then, however, he had been seized slowly and relentlessly by excruciating shoulder and hip pain. What had begun as stiffness in the morning – chalked up initially to lifting heavy printed material out of the trunk of his car – had completely overwhelmed him. Several weeks had passed without Harry's daily customer rounds. Despite his sterling reputation in the industry, Harry (a child of the Great Depression) worried about seeing his

customer base slip away and watching his business go down the tubes. My ears pricked up as I listened to Dr. Sidransky's description of the case. The symptoms struck some familiar chords: an elderly man, the recent onset of intense shoulder and hip discomfort, a rapid progression to disabilities. After hearing Harry's story, I agreed that *polymyalgia rheumatica* (PMR; see Box) was the likely diagnosis. Over the phone, I prescribed 15 milligrams of prednisone for Harry and made arrangements to see the Blooms in clinic the next day.

It is impossible for those who do not have PMR to understand fully the disabling nature of the pain caused by this illness. Symptoms descend on patients at variable speeds but close like a vise, robbing them of their ability to care for themselves. Because PMR frequently occurs in the elderly, it threatens to fulfill their worst nightmares of old age: pain, dependency, despondency. Fortunately, for those who have never been its witness, it is also impossible to appreciate the dramatic improvement wrought in PMR patients by prednisone. There are few more satisfying treatment responses in all of medicine.

The response of PMR patients to prednisone, I suspect, is the reason why many rheumatologists have chosen their specialty. The typical career-molding scenario is as follows: a young doctor evaluates an older patient recently rendered miserable by pains that have gripped the entire body. For the patient, life under such circumstances no longer seems worth living. The array of complaints is at first puzzling to the physician. Eventually, though, recognition stirs, as passages from a medical school text are recalled. For the first time, he diagnoses PMR. He tells the patient that he knows what is wrong; that he can make it better. Quickly. With prednisone. The patient cannot believe his ears: "This youngster (young enough to be my grandson!) is going to relieve this pain? Cure me? I can't believe it! *But I am so desperate I will try anything*".

True to the doctor's word, that is *exactly* what happens. The patient takes prednisone and by the next day the pain has lifted. The patient is able once again to raise his arms above his head, to comb his hair, to climb stairs, to walk. Deliverance from the pain is precisely what the patient prayed for, exactly what the doctor dreamt of during pre-medical studies and throughout medical school. For the doctor-in-training it is intoxicating and possibly even career-defining. For the patient, it is simply a miracle.

That evening, after taking the 15 mg of prednisone, Harry Bloom slept for the first time in a month. The next day, when I met him in clinic with Alice and his daughters, he walked into clinic unassisted and was able to raise his arms above his head, a feat he could not possibly have achieved only twelve hours before.

Mr. Bloom illustrated perfectly the familiar and gratifying "PMR response" to prednisone. Clinical wisdom holds that if a patient diagnosed with PMR is not substantially better within 48 hours of the first prednisone dose, the diagnosis is incorrect. In clinic, Harry already looked far better than the description provided by Dr. Sidransky the day before. But there were some worrisome symptoms that I had not appreciated on the phone. When asked, Mr. Bloom noted recent headaches. In addition, whenever he tried to chew anything, even soft foods, he quickly developed pain in his cheeks and jaw. Symptoms of headache and "jaw claudication", as this latter symptom is known, strongly suggest the possibility of a PMR-related condition: **giant cell arteritis** (GCA; see box). PMR and GCA form a spectrum of disease and often occur in the same patient. The possibility of GCA raises the stakes considerably for a patient with PMR because GCA, which involves inflammation of blood vessels that supply the eyes, may cause blindness. Without prednisone, Harry's risk of blindness was greater than 40%. Even with prednisone, 15-20% of patients still lose some vision because blindness strikes before the diagnosis is made. Concern about blindness and other potential complications of GCA led me to

Polymyalgia Rheumatica (PMR) and Giant Cell Arteritis (GCA)

- A spectrum of inflammatory illness that generally strikes individuals > 50 years of age. The incidence of PMR/GCA increases with each decade of life, peaking at a mean age of 72.
- There are estimated to be more than 500,000 cases of PMR/GCA in the United States. The prevalence of this condition will grow as Baby Boomers age.
- Currently, approximately 1 individual in 500 over the age of 50 develops PMR/GCA.
- PMR/GCA is 3-4 times more common among women than men.
- PMR is characterized by intense aching in the shoulder and hip regions such that the patients are unable to comb hair, walk up or down stairs, or otherwise care for themselves.
- GCA involves inflammation within blood vessels that supply the eyes with blood, oxygen, and other nutrients. The vasculitis associated with GCA may lead to the sudden and permanent loss of vision in one or both eyes.
- Some patients have only PMR, others have only GCA. Some have symptoms of both.
- Under ideal circumstances, the diagnosis of GCA is confirmed by biopsy of the temporal artery, the vessel that courses (as its name implies) just in front of the ear and over the temple.
- PMR/GCA may also be associated with fevers, weight loss, headaches, and a host of other symptoms or signs.
- PMR/GCA is usually associated with blood test abnormalities, particularly an elevated erythrocyte sedimentation rate and a low blood count (anemia).
- PMR/GCA both respond quickly to treatment with prednisone. GCA usually requires higher doses to control the disease.
- The average length of treatment with prednisone for PMR/GCA is two years.
- No therapy other than prednisone has been proven effective for PMR/GCA.

prescribe a dose of prednisone higher than that usually employed in the treatment of PMR alone.

I raised Harry's prednisone to 60 mg/day.

For a time, things could not have gone better for Mr. Bloom. He was the old Harry; energetic, visiting his customers again, seeing his friends, trading jokes with Alice. Shadowboxing with life. And then prednisone blindsided Harry and me with a phantom right cross.

Three weekends after the call that introduced me to Harry, I received another call, this time from Alice. Harry had become suddenly, deeply, and hopelessly depressed. Mood disorders are a well-known potential side-effect of prednisone, but in treating hundreds of patients with that medication I have never seen it cause depression the way it did in Mr. Bloom. Almost as with the flipping of a switch, Harry had gone from ebullient to nearly suicidal.

He had lost his grin, his gleam, and the affirming way he had nodded his head when speaking. Seated now in the examining room, this radically changed man shook his head continuously from side to side, staring at the floor or into space: *"I don't know, Doc. I just feel terrible... terrible"*. Once again his daily rounds to customers stopped. He had taken to his bed again at home, now not from PMR and pain but from prednisone and depression. He begged me to stop the prednisone and so did Alice, both on phone calls that came almost daily and at Harry's frequent clinic visits.

This was the proverbial "rock and a hard place". Harry's life-destroying depression demanded intervention. Prednisone was the cause, and needed to be addressed. Yet his PMR/GCA had not been treated adequately. The average length of prednisone therapy for patients with PMR/GCA is two years. Stopping prednisone only weeks into his treatment course would almost certainly lead to a

return of the pain; and worse, to the possibility of permanent visual loss.

I often tell patients that treating vasculitis is like climbing a mountain. Getting to the summit (controlling the disease with treatment) is not as difficult as getting back down. Continuing the analogy, it is one thing to start immunosuppressive medications such as prednisone, but quite another to stop the therapy without triggering complications from either the disease or its treatment. In Harry's scenario, I felt like a mountaineer trying to rescue an injured companion. We were lashed together, rappelling down the mountain much faster than I felt safe. But the depth of Harry's depression left us no choice.

Though his spirit was battered and his mind groggy from the prednisone, Harry helped himself, too. For a man of a generation that has often regarded mood disorders as character weakness, the need to be treated for depression heaped insult upon injury. He complied with the prednisone taper, even though every instinct told him to spit the tablets out. With Alice, Leslie, and Sandy in his corner, he also took all of the steps necessary to address his depression.

In his own inimitable way, Harry let me know he was back. Nine months after that Sunday afternoon telephone call, he ambled into clinic all by himself wearing the same lopsided grin I had first seen the day we met. He brought with him a box of pastries from a new bakery he had discovered while visiting



Harry Bloom in clinic

customers. I bit into a pastry and grinned back at him. We reviewed his progress and mused about how far he'd come from where he'd been. As he considered back further, over the distance he had traveled in life, Harry related a tale about a trip – decades ago – to the same neighborhood where he'd gotten the pastries. On that trip, he had encountered some young toughs who

didn't like him merely because his own neighborhood was Corned Beef Row. "*Things are better now*", and we agreed. At the end of our visit, I clasped his shoulder, declared him the winner, and sent him back in for his next rounds. ☀

JOHNS HOPKINS VASCULITIS CENTER

WEBSITE NEWS

JUNE 2004

- Updated Listing of Research Studies at The Johns Hopkins Vasculitis Center
- Frequently Asked Questions about Clinical Trials and Research Studies
- New Methotrexate Medical Brochure

JULY/AUGUST 2004

- Information on Microscopic Polyangiitis

COMING SOON

- Updated Glossary of definitions for patients
- Information on Polymyalgia Rheumatica

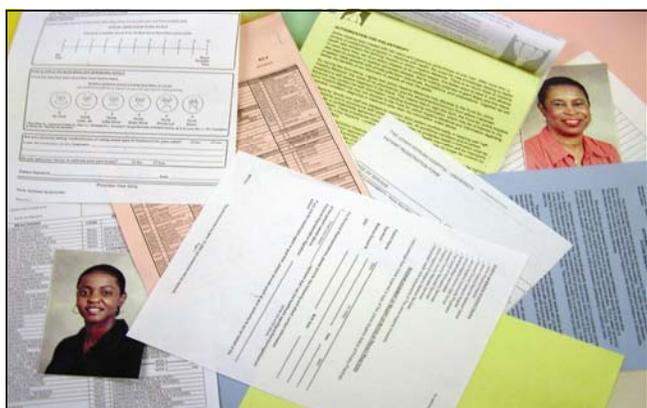
This summer, the Vasculitis Center and a team from the University of Maryland's Masters-level Information Management program forged a partnership in education. The UMD team will be providing website and information management expertise as part of their degree work and the JHVC will receive a new and improved website. Stay tuned for future updates!

You can find us at:

[HTTP://VASCULITIS.MED.JHU.EDU](http://vasculitis.med.jhu.edu)

When you arrive in clinic you are greeted by the smiling faces of our Patient Care Coordinators -- Cynthia Bethea and Sidone Lawrence -- who promptly and efficiently process your registration into the clinic. Besides collecting insurance and patient ID information, there are a series of forms to be read and signed. A question Cynthia and Sidone receive regularly is “*Why SO MANY Forms?? They seem to multiply every visit!*” There is a simple and very important answer: HIPAA and a patient’s right to privacy.

Because of the flurry of forms, we thought it would be a good idea to share some information about HIPAA, the Patient Protections amendments and some of the operational changes practices at the Vasculitis Center. Many patients know about HIPAA, but often do not get read about how the laws are knit into the practices of providing health care.



Forms, Forms, Forms....You may have noticed the escalation in the number of forms starting in spring 2003. In April of that year, amendments to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) took effect. The major changes in the amendment added patients' health information privacy rights. It was a very important step in patient rights and privacy issues. The Johns Hopkins Vasculitis Center (JHVC) actively endorses these regulations and regards them as an extension of the respect and care we have always worked to provide to our patients.

As a health care provider, we provide written documentation of how, when and where we use your medical information. “Medical information” is any-

thing dealing with your care and treatment at the Vasculitis Center or the medical records you entrust to us to assist in your care. Hence, new and colorful forms to read, understand and sign, if you are in agreement with what they state.

Other operational changes at the JHVC....

Newsletter and Mailings. People's perspective on what is “marketing information” is very personal. The Vasculitis Center aims to respect each person's wishes in our communications of health-related information, such as our newsletter and other mailings. The Newsletter is a general publication sent to our patients and friends, and its focus is to pass on medical news and information about vasculitis and people living with vasculitis.

In the past, The Vasculitis Center Newsletter included an annual acknowledgement list of our donors and, from time to time, articles about fundraising activities performed by family and friends. In the terms and conditions in the “*Prohibition of Marketing*” clause, no longer are we able to publish this type of information in the newsletter. This is a small change, but an important one because generosity should always be acknowledged. Physicians at the JHVC will continue to acknowledge gifts in private letters. Please be assured that the Vasculitis Center appreciates your generosity, but we are not able to acknowledge contributions in the Newsletter.

General Information about HIPAA

What is HIPAA? In brief, HIPAA is a law designed to support all citizens' rights in connection with health care. HIPAA regulations cover many issues, from the health benefits rights of citizens to how medical information is shared and used. The U.S. Department of Health and Human Services (HHS) has several facts sheets available on its website listed in the resources box at the bottom of this article.

Have the HIPAA Patient Protections changed my care? No, the changes were primarily administrative. You’ll still receive the same quality care from your JHVC team.

What are the Patient Protections provided with the HIPAA amendment? According to HHS's Fact Sheet on "Protecting the Privacy of Patients' Health Information" patient protections are:

- Patient Access to Medical Records
- Notice of Privacy Practices from Health Care Providers
- Limits on Use of Personal Medical Information
- Prohibition on Marketing
- Baseline Law for Stronger State Laws on Patient Privacy
- Confidential Communications
- Complaints Process

For further details on HIPAA and Patient Privacy, please see the contact information listed in the **Resources** inset below.

We hope we provided some new insight on “*Why SO MANY forms?*” as well as useful information about HIPAA and the Patient Protections enacted last year. If you have any questions or concerns about HIPAA, we encourage you to speak with any of the Vasculitis Center staff, e-mail us at JHVC@jhmi.edu or contact The Johns Hopkins Privacy Officer (listed below).☀

HIPAA and Johns Hopkins Medicine

<http://www.hopkinsmedicine.org/hipaa/>

- or -

Johns Hopkins Privacy Officer
600 N. Wolfe Street, Billings 400
Baltimore, MD 21287-1900
Phone: 410-502-7983
Fax: 410-955-0636
Email: hipaa@jhmi.edu

Department of Health and Human Services

<http://www.hhs.gov/ocr/hipaa/>

- or -

Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Room 509F, HHH Building
Washington, D.C. 20201
HIPAA toll-free number at (866) 627-7748
Toll-free TDD line: (800) 537-7697

Patient Perspectives

Patient Perspectives is a new feature in the newsletter that highlights vasculitis patient issues, our health care and our daily lives. This first article is my contribution, but I look forward to hearing from you. If you have something you'd like to share about your experiences as a person living with vasculitis, please email me, Stacey LaBahn, at jhvc@jhmi.edu or send a letter to:

The Johns Hopkins Vasculitis Center
ATTN: Stacey LaBahn
Bayview Medical Center
5501 Hopkins Bayview Circle
JHAAC, Room 1B.1A
Baltimore, Maryland 21224

Together we can make living with vasculitis easier by sharing our wealth of knowledge.

OK, So I Have Vasculitis. Now What?

When facing vasculitis, the question most people have is “what to do I do now”? There are many changes in life that come with chronic illness. As a person who’s a 5 year “veteran” of disease management, the best action is to take things one step at a time. There is a transition that occurs when you shift from discovering you have vasculitis to living with vasculitis. In time, your medical regimen will become part of everyday life. It will always be an important part of who you are, but it won’t be the center point. Since vasculitis may be new to you, here are three suggestions that will help you start progressing down the path from “patient” back to “person” in a positive way.

First and foremost, educate yourself. Learn as much as you can about your type of vasculitis. An informed patient is, many times, a healthier patient. It has been shown that people who understand their illness and participate in developing their treatment plans with their medical practitioners have improved health outcomes.



Getting an education about vasculitis is an education in itself. Because many types of vasculitis are considered a rare disease, information is not as readily available as for other chronic conditions like diabetes. A good place to start is the Vasculitis Center's website at <http://vasculitis.med.jhu.edu>. The Internet is an amazing communication tool, but remember it is truly an information democracy at work. Anyone can post anything at anytime, so use your "common sense filter" when learning about medical issues. If there are specific issues you are concerned about, ask the practitioners in your vasculitis care team. They can provide answers as well as quality information sources if you are having difficulties finding what you need.

Participate in building your treatment plan.

Once your condition is stabilized, you will move into on-going maintenance called a treatment plan. This plan is designed between you and your medical practitioners. It identifies the various personal practices, health objectives and medications that make up your care.



It is important to be an active participant because it is your health and well-being that is being decided. By participating, asking questions, stating your likes and dislikes, your medical team will have a better understanding of what your needs are and can provide alternative treatment paths, if options are available. The better a treatment plan suits your life, the easier it is to follow.

You are your healthcare. Once your treatment plan is designed, it is up to you to make it happen. Your life is outside of medical care facilities. To be as healthy as possible requires diligence and determination.



Everyday, it is up to you to follow your treatment plan. Only you can take your medications and monitor your progress. You need to be aware of changes in your health and to

determine if the changes may be important to communicate to your medical practitioners.

In the early stages of managing a chronic illness, it is difficult to know what is important. As you become a "veteran" in managing your vasculitis, it will become easier to identify health changes, when they should be communicated, and to which doctor in your medical team. For patients, learning what is normal or not normal in your health is one of the bigger challenge of chronic illness management .

These three points may seem simple, but they are the key to well-being in living with vasculitis.

Chronic illness has the ability to "disable" people because they lose a sense of who they are or how they define themselves. By learning and understanding what is happening to you, each day can be managed better based on what you



are given. Knowing you are doing all you can to have the best health possible is a powerful and positive experience as a patient. It gives you the chance to focus on and participate in what is manageable. When you experience success in your health care, it is because of the decisions you make day-to-day that make it a success. You are the most important partner in your healthcare team.☀

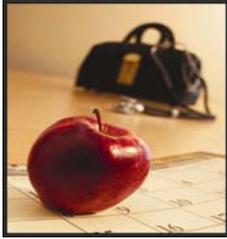
Would you like to be a Vasculitis Center Volunteer?

The Johns Hopkins Vasculitis Center is seeking people interested in helping with projects from patient outreach and communications to support on clinic days.

Let us know your talents and interests and we'll work together to make it happen.

Please contact:
Stacey LaBahn, Communications Coordinator
 5501 Hopkins Bayview Circle
 JHAAC, Room 1B.22
 Baltimore, MD 21224
 410-550-6816
jhvc@jhmi.edu

Follow-up on our featured patients

**What is a Year?**

Contributed by: Stacey LaBahn
Of Ears and Emails—Spring 2003

Not long ago, the idea of volunteering at the Vasculitis Center, attending graduate school, and most surprisingly -- hearing sounds again seemed a remote possibility. In the Vasculitis Center newsletter (Spring 2003), Dr. Stone told my story in "*Of Ears and Emails*". This story was recently re-published by [Annals of Internal Medicine](#) for other physicians to read and gain perspective on patient/physician communication. He asked if I'd provide a follow-up.

Just as life moves forward, so does the story. As Dr. Stone relayed in "*Of Ears and Emails*", my latest flare began before Thanksgiving 2002 and it did not stop at deafness. Random joint pain, sporadic headaches and an inflamed right knee pushed us to try localized steroid injections and increased oral medications, but the flare persisted. As if it was yesterday, I remember slowly and painfully working my way down the short hallway from my bedroom to my home office to get to my computer. I emailed Dr. Stone. I told him, "I am hitting a physical and mental wall and can not see a way around it. In 48 hours I need to walk through an airport to board a plane so I can visit my parents for the holidays. It does not seem physically possible."

In his ever caring way, he wrote to me that to we would need to increase the prednisone. He knew it was my least favorite instruction. Knowing in my heart there was no other option, I agreed. A quick taper through 60 mg's to 20 mg's got me through the airport, through the holidays into the New Year.

In January and March 2003, the periodic headaches became all-day affairs. Once again, prednisone and cytoxan put the world right again, but I was getting tired; tired of flare ups, tired of medications, and tired of not feeling "me" anymore. Something had to change and I realized it was up to me to decide when it would happen.

By April 2003, I decided it was time to change. I had given 6 months of my life to this specific flare and I was determined this disease was no longer going to rule my life. I started by working on the physical "me" by losing the 35 lbs. I gained during the aggressive steroid therapy required from December to March. By July 2003, I was well enough to attend summer session at Gallaudet University to work on my sign language and speech reading. By fall, I had tapered from cytoxan to imuran for maintenance of my flare ups. And, I applied to graduate school for Spring 2004 admission. Most importantly, since the headaches were under control, I was able contact The Johns Hopkins Listening Center to complete my assessment for approval as a cochlear implant candidate, which was delayed due to the headaches in the early part of 2003.

A surprise email came from Dr. Francis' office on November 2, 2003. They had received a cancellation for cochlear implant (CI) surgery for the next day. I was offered the time slot if I was ready. I don't know if one can ever be ready for surgery, so I decided to take the offer. The surgery went well and the healing complete. My implant was activated in December 2003. From early on in my CI adaptation I heard sounds well enough to understand most speech in face-to-face, quiet, controlled environments. With the passage of time, my comprehension has continued to improve. By the end of the 2003, I was ready to take on all the challenges I had lined up for the 2004.

Now I ask myself, "What is a year"? I read somewhere that success is not defined by the height attained but by the obstacles overcome. To those of us with vasculitis, many times, a year is a measured by obstacles overcome. We celebrate another period of remission or survive a flare with the help of our medications and medical practitioners. We are on the other side of illness; the up-side, the controlled. We are participating in life. We manage what we are able to do 365 days, one day at a time. We keep moving forward because life demands it, regardless. I know I am more resilient than before I had vasculitis. For me, a year is no longer the passage of 12 months, but a calendar of opportunities to reach for what I want and to see what the new year has in store.☀



Welcome Aboard, Dr. Seo!

“If you really want to know,” goes the saying around the Vasculitis Center, “ask Phil Seo”. During the 2003-2004 academic year, the Vasculitis Center has been delighted to welcome Dr. Philip Seo (pronounced “see-oh”), to the clinical and research endeavors of the group. Dr. Seo is one of the very best trainees produced by the Johns Hopkins Department of Medicine in recent memory. He trained on the Osler Medical Housestaff from 1997-2000, followed by a year of work as a “hospitalist” at Johns Hopkins Bayview. He then served with distinction in the prestigious role of “Assistant Chief of Service” — Chief Resident — at Johns Hopkins Hospital.



As of September 1, Dr. Seo is an Instructor in Medicine appointed to the Vasculitis Center. We are delighted to have him aboard.

Off to the Emerald Isle

Dr. Michael Regan has accepted an academic position as Consultant Rheumatologist in Ireland as of August 31, 2004. Dr. Regan said, “Although I am very excited about this terrific opportunity, the move is tinged with no small amount of sadness for me.”

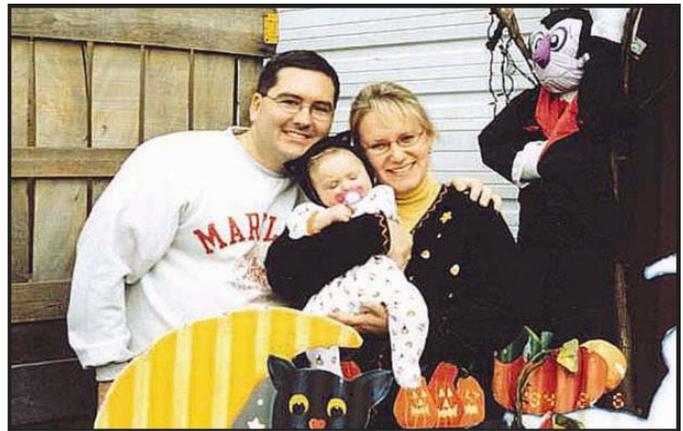
The Vasculitis Center is committed to ensuring a smooth transition of care for Dr. Regan’s former patients. His former patients should contact one of the Vasculitis Center’s Patient Care Coordinators (either Cynthia or Sidone) for a new follow-up appointment with one of the Vasculitis Center faculty. The telephone number to call is 410-550-6825.

Help has Arrived!

We would like to introduce Matt Marriott, Physician Assistant, PA-C to the Vasculitis Center’s patients and

the surrounding community. Matt comes to us with a diverse background in medical and re-

search training. From serving as a lieutenant in the army reserves and providing medical care during Operation Enduring Freedom to acting as Research Program Coordinator for the Brain Attack TeamSM at the University of Maryland for stroke patients, Matt’s focus is the always on the patient.



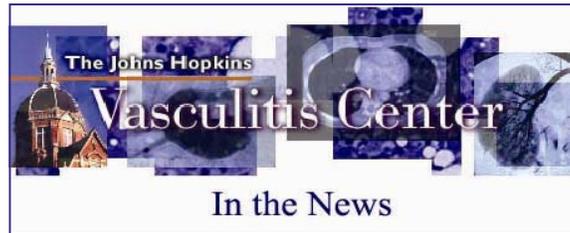
The Marriotts: Matt, Shannon and Kaitlyn;
Halloween 2003

Matt graduated with honors from Beaver College (now known as Arcadia University) in 1998, earning a masters degree in Physician Assistant. As an undergraduate at the University of Maryland College Park, he started his path in medical care as a student trainer for UMD’s nationally-ranked athletic programs. A Dean’s List regular, Matt closed his undergraduate career by earning not one, but two bachelors degrees!

Matt and his wife Shannon are the loving, doting parents of a 22 month old baby girl named Kaitlyn Amanda. He tells us that “*she is the most beautiful creature on Earth! I thank God every day for giving Kaitlyn to us*”.

From Volunteer to Vasculitis Staff

Everyone who has read the Spring 2003 issue of The Johns Hopkins Vasculitis Center Newsletter was introduced to Stacey LaBahn through the article “*Of Ears and Emails*”. (Archived JHVC Newsletters are



visit and we'd be happy to discuss it with you.

available on the web under **Resources**, and then **Our Newsletters** or at:

<http://vasculitis.med.jhu.edu/resources/publications.html#newsletters>). The article highlights how vasculitis has changed her life in many ways, and she believes for the better. These changes have lead her to pursue a masters degree in Information Management. Her experience has sparked her interest in putting her background in technology and marketing to work for patients and patient healthcare issues.



Stacey LaBahn and the San Francisco skyline.

In September, Stacey transitioned from volunteer to staff member in the role of Communications Coordinator for the Vasculitis Center. She will focus on patient education and communications. From managing the Vasculitis Center website to coordinating patient informatics-related projects and studies, Stacey will be spreading the word about vasculitis, the Center, and patient advocacy for people with vasculitis.

Welcome!☀

Publications from the Johns Hopkins Vasculitis Center Staff

Wondering why we're a little late with the Newsletter this issue?

We are very pleased to report on a variety of writings and publications produced by the Vasculitis Center staff. These publications are extremely important to people who have vasculitis. As a Center specializing in vasculitides, our participation in academic publishing brings awareness and information to the global medical community about vasculitis. It helps general medical practitioners with identification and treatment of vasculitis in their patients. This working is the foundation for building sources of quality information on vasculitis to use in understanding your health issues. If you would like to know more about an article listed here, mention it in your next

Drs. Stone and Hellmann recently co-edited a new medical textbook entitled Current Rheumatology Diagnosis and Treatment (Lange Medical Books/McGraw-Hill). Planning is already underway for a second edition of this book. Drs. Seo and Stone have authored review articles on ANCA-Associated Vasculitis (*American Journal of Medicine*) and Large-Vessel Vasculitis (*Arthritis Care and Research*).

The case of a Vasculitis Center patient with Wegener's Granulomatosis, which first appeared in these pages as "The Odyssey of David Standon", was presented at Grand Rounds in May and will be published soon in the *Journal of the American Medical Association (JAMA)*.

The *Annals of Internal Medicine* has also noticed our work, publishing or accepting for publication three separate pieces: a manuscript describing the increased incidence of venous thrombotic events in patients with Wegener's Granulomatosis; the "Of Ears and E-mails" article (referred to on page 9); and an editorial by Dr. Stone: "Methotrexate in Polymyalgia Rheumatica: Kernel of Truth or Curse of Tantalus?".

Arthritis & Rheumatism recently published an editorial by David Hellmann entitled "Low-Dose Aspirin In The Treatment Of Giant Cell Arteritis". Dr. Hellmann was also a co-author on "The Case For Diversity In Academic Internal Medicine", which appeared in the *American Journal of Medicine*.

In addition to these, there are several more papers "in the works", at various stages of the review and revision process. And these are just the peer-reviewed writings – never mind the grants! Nevertheless, with our newly-hired Communications Coordinator, we anticipate no future lapses in the cycle of Newsletters. Next deadline: mid-January for the Winter 2005 edition.☀

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Medication Tip

Remembering Your Refills

- ⊕ Before putting your medications away, add a "REFILL" note on your family or personal calendar a few days before you run out.
- ⊕ Use computers? Set up automatic reminders that send emails or pop-up messages.
- ⊕ Ask for help from a friend or family member to remind you to refill.

Clinic Corner: The Role of a Physician Assistant

Q. What is a Physician Assistant (PA)? Physician assistants are health care professionals licensed to practice medicine with physicians as partner in care. As part of their comprehensive responsibilities, PAs conduct physical exams, diagnose and treat illnesses, order and interpret tests, counsel on preventive health care, assist in surgery, and in virtually all states can write prescriptions (this is true in Maryland).

Q. What is the working relationship between a physician and a physician assistant? Within the physician-PA relationship, physician assistants work independently in medical decision making and provide a broad range of diagnostic and therapeutic services. The relationship between a PA and the supervising physician is one of mutual trust and respect. The physician assistant is a representative of the physician, treating the patient in the style and manner developed and directed by the supervising physician. The physician and PA practice as

members of a medical team.

Q. Are Physician Assistants (PA) trained like Physicians? PA students are taught, as are medical students, to diagnose and treat medical problems. PAs are trained in intensive, accredited education programs.

Q. When did the Physician Assistant profession begin? In the mid-1960s, Dr. Eugene Stead of the Duke University Medical Center in North Carolina started the first PA program.

Q. What does "PA-C" stand for? What does the "C" mean? Physician assistant-certified. It means that the person who holds the title has met the defined course of study and has undergone testing by the National Commission on Certification of Physician Assistants.

Edited from the **American Academy of Physician Assistants** website at
<http://www.aapa.org>

HTTP://VASCULITIS.MED.JHU.EDU
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