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Vasculitis Center To Johns Hopkins Bayview

Dear Patients and Friends:

At last, we are here – in our new “digs” at Bayview. We thought the day would never come, and many of you probably did, too. Although The Vasculitis Center is now only minutes away from its previous location on the downtown medical campus, the new space is a major upgrade in terms of facilities and a huge improvement in our ability to serve patients.

The Johns Hopkins Bayview Medical Center has a long, rich history. The hospital was founded in 1773 and until the 1980’s was known as the Baltimore City Hospital. (Some vestiges of this old name linger on the campus; see figure below). Johns Hopkins became affiliated with the hospital in the late 19th century, shortly after the opening of the medical school, and took responsibility for the Department of Medicine in the 1950’s. In the 1960’s, all of the Clinical

Departments became staffed by Hopkins doctors. In 1984, Johns Hopkins bought the hospital buildings and land. Initially, the hospital was renamed the Francis Scott Key Medical Center, a nod to the hospital’s view of Fort McHenry in Baltimore’s Harbor (the bombardment of which inspired “The Star-Spangled Banner” during the War of 1812). In 1994, the “Hopkinsization” of the hospital became complete when it was renamed The Johns Hopkins Bayview Medical Center.

Today, several divisions of the Department of Medicine are centered at Bayview, including the Division of Pulmonary and Critical Care Medicine, the Division of Allergy and Immunology, and the Division of Geriatric Medicine. Bayview is also known throughout the region for its Burn Unit. In addition, two Institutes of the National Institutes of Health (NIH) - the

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Smoking Cessation Equals Success

Patients often ask the doctors at the Vasculitis Center just how bad cigarette smoking is for people with vasculitis. The answer: very bad, indeed, as the following case describes.

Kelly Huber was a healthy 20 year-old woman until the summer of 1999. At that time, she first noticed painful, red, raised bumps on her lower legs, and swelling of her ankles and feet. Although the bumps disappeared for a while on their own, they soon returned. Over the following months, Kelly had recurrent episodes of these painful lesions every few weeks, and the episodes seemed to worsen each time. The bumps grew so painful that she quit her job as a supermarket clerk because of the discomfort caused by standing all day. The bumps mystified not only Kelly, but her doctors, as well.

In January 2000, she developed a brand new problem: a painful right second toe. A small blister formed over an area of redness, and then healed spontaneously after a few days. Within several weeks, other toes on both feet started to have similar problems. In early March 2000, a black area appeared on the inside aspect of the left big toe and the under surface of her left little toe became mottled (see figure). Whereas Kelly once had toe pain only with walking, she now had it constantly, even while at rest. Her pain became so bad that she required narcotics around the clock. Then, a new primary care doctor referred her to the Rheumatology Division at Johns Hopkins, where she met Dr. Michael Regan.



Kelly's toes at the time of her first appointment at the Vasculitis Center.

In reviewing her full medical history, Dr. Regan noted that Kelly had smoked one pack of

cigarettes a day for 4 years. When he examined her, he found that the pulses in her feet were absent, and the skin below the mid-feet was cool to the touch. Sizing up the details of her case, Dr. Regan quickly narrowed the list of possible diagnoses to two, Buerger's disease and polyarteritis nodosa. He admitted her immediately to the hospital for further evaluation — and give her strict orders not to smoke.

An angiogram of her legs (see Figure) showed that her blood vessels looked worse than her feet — **m u c h w o r s e**. Inflammation in the arteries of her lower legs had caused critical narrowings in some areas and complete blockages in others. Only the redundancy of the legs' vascular supply was keeping Kelly's feet and toes alive. The results of the angiogram, the lack of evidence that any other organs were involved, and her history of significant tobacco use, led Dr. Regan to the diagnosis of Buerger's disease.



Blockages in Kelly's arteries are indicated by Xs.

Buerger's disease, described by pathologist Leo Buerger in 1908, was first noted in leg amputations from young male smokers (*Women smoked less than men in 1908. Such, alas, is no longer the case*). The strong association with cigarette smoking was recognized only years later. Buerger's disease does not occur in the absence of smoking. Moreover, for people who get Buerger's disease, stopping smoking is the best, in fact, the only treatment.

Once her problem had been diagnosed accurately,

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Kelly said good-bye forever to cigarettes. (Two years later, she has never violated this promise to herself even once). Within 3 weeks of quitting smoking, Kelly was able to discontinue all painkillers and her toes had begun to heal. Within 4 months, the gangrene on her toes was gone, and the normal color of her toes had returned. She has now returned to her full state of health, with her feet (and probably more) saved by a timely diagnosis and her own self-discipline.

One year after her close call at Hopkins, Kelly came to the hospital for another event – this one happy: the birth of her daughter, Kaitlyn.



Kelly and Kaitlyn

Bayview: (Continued)

(Continued from page 1)

National Institute on Aging and the National Institute on Drug Abuse - are located on the Bayview campus.

As the Chairman of Medicine at the Johns Hopkins Bayview Medical Center, I am fond of saying that Johns Hopkins Bayview has 3 major assets:

1) open land; 2) a hospital of manageable size; and 3) a view of the Bay. In actuality, during my own two years as the Chief of Medicine here, I have come to appreciate many more assets.

For patients:

- Ready access to the Bayview campus without having to drive downtown
- Better parking (see page 4)
- Phlebotomy services right in clinic
- Clinic staff that focuses only on rheumatology, not every other medical subspecialty. This leads to greater clinic efficiency and translates into shorter waiting time for patients.
- The same outstanding Patient Care Coordinators – Judy and Chas.

For researchers:

- Clinic space directly contiguous to our research and administrative offices
- Central facilities for the storage of research samples (again, right in clinic).
- Opportunity to share resources with the Scleroderma and Arthritis Centers.
- A wealth of talented researchers in the Divisions of Pulmonary Medicine and Allergy/

Immunology, all located in the same building.

- Opportunities for collaboration with investigators at the neighboring NIH institutes.

Our faculty have already fit right in at Bayview. In addition to my own role as Chief of the Zieve Medical Service, Dr. John Stone has been named the Director of Clinical Research for the Department of Medicine at Bayview and has instituted two research seminar series. Dr. Michael Regan, recently promoted to Assistant Professor, has completed his first stretch on the Bayview Campus of attending on the Inpatient Medical Service and was greeted with enormous enthusiasm by the students and Housestaff.

We look forward to growing in our new space, and to welcoming you to it. Please see the other information in this edition of the Newsletter about how to get here and where to park.

David B. Hellmann

In addition to striving for excellence in patient care and medical education, Johns Hopkins is an active center for research. Much of our work toward progress in the understanding and treatment of vasculitis is funded through grants. Other research support is made possible through private donations, large and small. If you would like to make a contribution to vasculitis research, please send your tax-deductible contribution, payable to The Johns Hopkins Vasculitis Center. Our address is: 5501 Hopkins Bayview Circle, JHAAC Room 1B.1A, Baltimore, MD 21224. Questions about philanthropic giving may be directed to Mandy Moore at (410) 550-6816.

Contact Information At Our New Location:

Address:

The Johns Hopkins Vasculitis Center
 Bayview Medical Center
 5501 Hopkins Bayview Center
 JHAAC, Room 1B.1A
 Baltimore, MD 21224

Scheduling Phone Number: (410) 550-6825

Research Phone Number: (410) 550-6816

Fax: (410) 550-6830

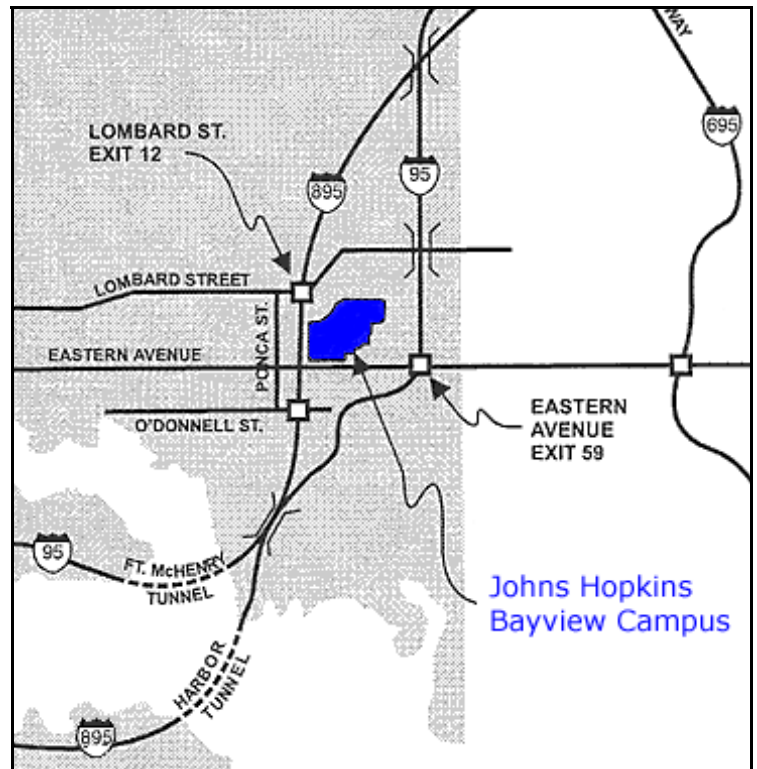
Directions to Bayview:

From the South (including BWI Airport):

- Take I-295 north to the Harbor Tunnel Thurway (I-895). After exiting the tunnel, take exit 12 (Lombard Street). At the first stop light, proceed straight onto Bayview Boulevard.
- OR
- Take I-95 through the Fort McHenry Tunnel to exit 59 (Eastern Avenue). Turn left onto Eastern Avenue and proceed approximately one mile to Bayview Boulevard on the right.

From the North and East:

- Take I-95 south to exit 59 (Eastern Avenue). Turn right onto Eastern Avenue and head west, proceed approximately one mile to Bayview Boulevard on the right.
- OR
- Take I-895 south to exit 12 (Lombard Street). At the first stop light, turn right onto Bayview Boulevard.

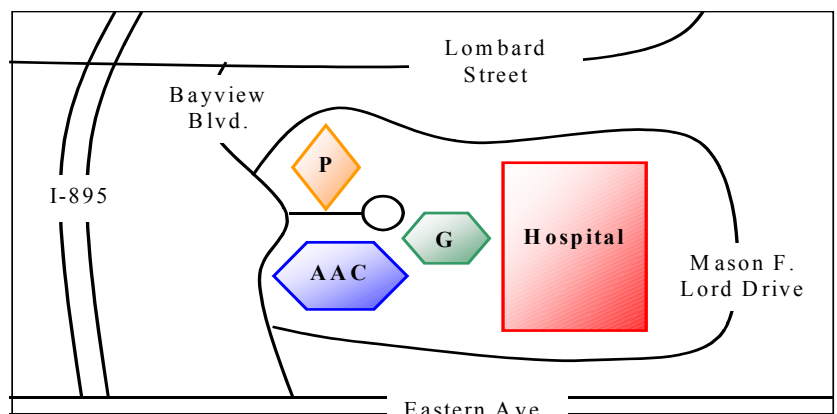


Once on the Bayview Campus:

- You will see the Johns Hopkins Asthma and Allergy Center straight ahead.
- Go through one traffic light and take the next right, just past the building. Turn left into the mid-campus parking lot.

In the JHAAC:

- The Vasculitis Center is located on the first floor, one floor down from where you enter.
- Take the elevator down to floor 1. The center entrance is located straight ahead through the glass doors.



Legend	
P	Parking
AAC	Asthma and Allergy Center
G	Geriatric Center

Vasculitis Center Collage

One of our greatest pleasures is seeing patients doing things they enjoy — away from the hospital and clinic!



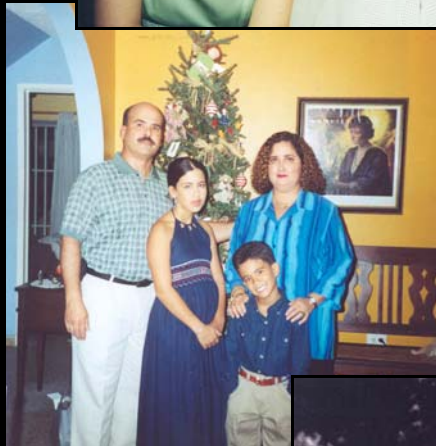
Roger Griffith enjoying a bright afternoon on his sailboat.

S.W. with her fiancé, J., enjoying a sunny August day at her home in Lansing, NY.



Tracey Reisinger with her fiancé, Chad Reibold, at a friend's wedding. (May, 2001)

Sonia Rodriguez with her husband Luis Carrillo and their children, Maria Fernanda and Fernando. Christmas, 2001.



Mark Meyers stirring gravy at the West Campeter Community Fair. Mr. Meyers is on the Board of Directors for the Fair.



T.V.M. playing sax with his band members, Jerry DiLeonardo (drummer) and Bobby Berger (keyboard) in Essex, MD.



Kelly Harrigan-DiCostanzo with her husband, James, at their wedding on September 8, 2001.

Linda Gray with her husband, Robin, at their home in Ellicott City, MD.



FREQUENTLY ASKED QUESTIONS

Why do I have to have bloodwork checked frequently?

It's simple (you've probably heard us say it before): "A watched kettle doesn't boil". The more detailed answer is that in the management of patients with vasculitis, we are concerned not only with treating the disease, but also with preventing side effects of treatment. The lab work that we assess regularly is designed to help us accomplish both of these goals.

What types of tests do we check?

Regardless of the type of vasculitis and the exact type of medication that a patient takes, similar types of tests must be monitored. These tests are: 1) a complete blood count; 2) tests of kidney function including a urinalysis; and 3) liver function tests. The table below outlines the importance behind checking each of these tests. Sometimes other tests are required, too, for special circumstances, as when a patient is on a "blood thinner" such as coumadin.

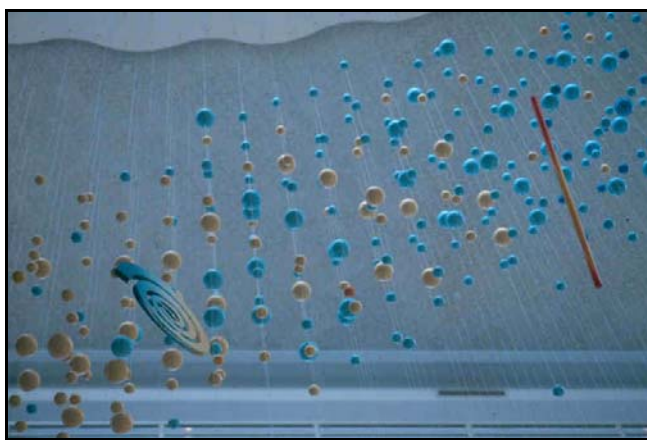
How often should my blood be checked?

This depends on the specific medicine or medicines that you take. Patients on cyclophosphamide (Cytosan) should have their

counts checked every 2 weeks. Patients on most other kinds of medications used to treat vasculitis (Methotrexate, Azathioprine) usually only need to have their blood work checked monthly. If some laboratory tests are abnormal or nearly so, then more frequent monitoring may be required.

Where should the results be sent?

The results of the lab work should be faxed to Judy or Chas at (410) 550-6830. Please check with your laboratory to make sure your results are sent to the Vasculitis Center on time. You may need to double check.



Artwork in the atrium of the Asthma and Allergy Center at Bayview.

Type of Test	What should be checked	Why?
Complete Blood Count ("CBC")	<ul style="list-style-type: none"> White blood cells (WBC) Platelets Hematocrit 	<p>Low WBC count may lead to infections</p> <p>Low platelets may cause bleeding</p> <p>Low hematocrit means insufficient oxygen-carrying capacity of the blood</p>
Kidney Function	<ul style="list-style-type: none"> Creatinine Blood Urea Nitrogen (BUN) 	<p>High creatinine and BUN indicate that the kidneys are not performing their blood-cleansing function properly</p>
Urinalysis	<ul style="list-style-type: none"> Protein level Red blood cells 	<p>Normal urinalyses have no protein and no blood. The presence of protein and/or blood in the urine may indicate active vasculitis in the kidneys (or damage to the bladder from cyclophosphamide)</p>
Liver Function	<ul style="list-style-type: none"> Albumin Aspartate aminotransferase (AST) Alanine aminotransferase (ALT) 	<p>Often a good indication of overall health</p> <p>Elevated AST/ALT levels indicate inflammation in the liver (usually caused by medications)</p>



I received a call from my best friend, Katiera telling me how much she loved me and how glad she is that I am in her life. Even though she is my best friend, I was initially puzzled by the reason for her call. And then she explained: her co-worker's best friend had just died of Wegener's granulomatosis. Suddenly, I understood Katiera's mood. The similarities between the other young woman and me were eerie:

She was black, as I am. The woman who was her best friend works at a major telecommunications company in Maryland; my best friend sits only a few cubicles away. She went to the University of Maryland, Baltimore County (UMBC); I did too. She was in her 20's; I am now 25. The only obvious difference between us in an important and sad one: She is dead; I am not.

My first thought was: "Wow, another young African-American woman with Wegener's in Baltimore? I thought I was the only one!" Wegener's is, after all, very rare in African-Americans. My second thought: "There but for the grace of God go I." The news of this woman's death transported me back to April 1999, when my own future was uncertain, at best. As I neared the end of my first semester of graduate school at Rutgers, I came down with what I thought was the flu: incredible fatigue, which I attributed to my heavy workload. Unlike everyday cold and flu bugs, this one did not get better, and no amount of over-the-counter remedies helped. One of my eyes became red and swollen, followed shortly by the other. It was then that the aches and pains began. After those two problems came strange bumps on my elbows and then... I rapidly became the poster child for Wegener's granulomatosis: lung involvement; kidney disease; painful fingers and toes that turned purple; and the worst: lightning-like pains that seared through my body without warning.

Fear dominated my every thought. I do not have to imagine how this young woman, her family, and friends felt as they stared with fright into the faces of bewildered doctors and confronted treatments – antibiotics, cough medicines, painkillers – that in the end turned out to be blind alleys. The night before I went into the hospital in 1999, I had told my best friend that she would find me there tomorrow, but I was really

wasn't sure she would. Did this young woman feel herself slipping away, as I did? Did she know?

Humility saved me. There were other things, too, but the humility of my primary care doctor was the first step. He was brave enough to follow his medical intuition, defy the orders of my health insurance company, and send me to Johns Hopkins. It was there that the wonderful interns, residents, Dr. Derek Fine, and doctors from the Vasculitis Center unraveled the mystery of what was wrong with me. They saw through the mechanisms my disease had for mimicking other illnesses, and actively engaged it with the force of knowledge and experience. Three years later, I have learned a lot about Wegener's – more than I ever wanted to know, quite honestly. I am in remission, and have stopped my cyclophosphamide and prednisone. I go to the Vasculitis Center every 4 months or so. Eventually the pain from damaged nerves in my arms and legs went away, as Dr. Stone said they would. After a brief interruption, I went back to school. This May, I graduated with a Masters degree in Psychology from Rutgers. Although I am back home now in Baltimore for the summer, I have already begun work toward a Psy.D. in Clinical Psychology.

I couldn't bring myself to read her premature obituary, but I know what it must have said. In my darkest days, I imagined my own obituary. By the time she was diagnosed, it was too late to save her. She was diagnosed with Wegener's granulomatosis at autopsy. This still happens, though apparently less often than it used to. The terrible irony is that, in the same city where Wegener's granulomatosis claimed her life resides one of the country's major research centers for the diagnosis and treatment of this disease. I can't help but wonder if her fate might have been different had she been sent to Hopkins – if her doctors had been as broad-thinking as mine.

I distill the many lessons from my experience with Wegener's into two messages. First, to those of you newly-diagnosed with this disease and to you veterans with active disease, you can beat it with a strong, experienced and caring medical team. Second, through promoting understanding of this terrible disease by patients and doctors alike, we Wegener's survivors have a role to play in working toward the day when cases like my Baltimore sister's never happen – *ever again*. –

Clinic Corner: Understanding your medical insurance 101

Understanding your medical insurance sometimes seems as difficult as comprehending tax laws. Both employ technical jargon for concepts that ought to be described in simple, straight forward language.

Hidden among the technical jargon of your health care policy is an explanation of your benefits that determines how much you pay, what extra benefits you may have, and which doctors you can see. Peel away the jargon and you will find three main types of health insurance:

Health Maintenance Organization (HMO): HMO coverage means that you must choose a hospital or physician from a list provided by your insurance company. Often, your HMO will require you to select a **primary care physician (PCP)** to coordinate all of your care. Visits to doctors not on the list and other medical services (chest x-rays, laboratory tests) require written referrals from your PCP.

Preferred Provider Organization (PPO): If you are part of a PPO, your insurance will cover more services if you use the physicians and hospitals in the PPO network. Unlike an HMO, you have the freedom to choose a physician outside the network. However, this choice has a price—you will pay more out-of-pocket expenses since your insurance will cover less.

Indemnity Insurance Plan: An indemnity plan means you can choose your physician or hospital, without being confined to a network. But you may have to pay a portion of the bill. For example, you may pay 20% of your bill, while your insurance pays 80%.

Before you come to clinic, please:

- Have in hand any referrals or pre-authorizations required by your insurance
- Know whether or not your insurance will permit you to have bloodwork and other tests done at Johns Hopkins Bayview.

WE'RE ON THE WEB!
[HTTP://VASCULITIS.MED.JHU.EDU](http://VASCULITIS.MED.JHU.EDU)

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**THE JOHNS HOPKINS
VASCULITIS CENTER**

