

## INNOVATIONS IN SOUND AND MEDICINE

Contributed by Dr. David Hellmann

### Faculty

**John Stone, MD, MPH**

Director

**David Hellmann, MD, MACP**

Executive Director

**Stuart Levine, MD**

Assistant Professor

**Geetha Duvuru, MD**

Assistant Professor

**Philip Seo, MD**

Instructor

### Physician Assistant

**Matthew Marriott, PA-C, MS**

Physician Assistant-Certified

### Research Staff

**Lourdes Pinachos, RN, BSN**

Research Program Supervisor

**Delphine Paul**

Research Program Coordinator

### Visiting Rheumatologist

**Alicia Rodriguez-Pla, MD, PhD**

Post-Doctoral Fellow

### Clinical Coordinators

**Judy Harrison**

Rheumatology Clinic Supervisor

**Sidone Lawrence**

Patient Care Coordinator

**Cynthia Bethea**

Patient Care Coordinator

**Felicia Agen-Davis**

Medical Assistant

**Lisa Alexander**

Medical Records Coordinator

**Estelle Williams**

Patient Services Coordinator/Registrar

### Information /Communications

**Stacey LaBahn**

Communications Coordinator

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I am a Professor in the Johns Hopkins School of Medicine, which means I am supposed to “profess”, that is – to teach.

Indeed, I do spend a lot of time teaching medical students, residents, fellows, and other physicians about vasculitis and other medical topics, but I spend even more time being a student, learning much from a wide array of people.

My best teachers – unquestionably – have been my patients, who amaze me with their ability to teach me about medicine and life.

**Dr. Sidney Harman**, has been my patient for the last ten years and has also been one of my most effective teachers. A man of many talents and accomplishments (including his role as Executive Chairman of Harman International, a former college President, and the past Deputy Secretary of Commerce in the Carter Administration), Dr. Harman has taught me many lessons through the years. In this short piece, I will tell you what he has taught me about medicine and the value of innovation.



Dr. Sidney Harman

One of the most prominent lessons that emerges from Dr. Harman’s medical history is how **polymyalgia rheumatica (PMR)**

presents. Regular readers of these pages will recall that PMR is a disorder of inflammation that affects the muscles and joints, chiefly around the shoulders, neck, and hip areas. The results are severe pain and stiffness in these regions. When I met Dr. Harman, he vividly described the pain and stiffness as producing the

sensation of “a negative force field” around his body. If this description conjures for you (as it did for me) the image of Superman’s debilitation by contact with Kryptonite, then you have a pretty good sense of how horrible and disabling PMR can be.

The Superman image is especially fitting for Dr. Harman, who maintains a superhuman daily schedule that typically begins with vigorous exercise, continues with a grueling series of business meetings, and often extends into late-night dinners with business

associates and friends. As Chairman of a major company and the husband of Congresswoman Jane Harman, a U.S. Representative from California and the ranking minority leader on the House Subcommittee on Intelligence, Dr. Harman has a schedule that is easily above the 99<sup>th</sup> percentile in “busy-ness”.

### *Polymyalgia Rheumatica (PMR)*

Polymyalgia rheumatica is a syndrome of intense aching and pain in the regions of the shoulders and hips. The pain is typically so disabling that patients are unable to perform such simple tasks as combing their hair. Sometimes polymyalgia (meaning literally “many muscle aches”) occurs with giant cell arteritis (GCA). Given that the prevalence of PMR in the U.S. is **450,000 cases** at any given time, it is astonishing to think that recognition of this disease by doctors occurred only 45 years ago. Before PMR was identified, patients were misdiagnosed as having “rheumatism” or given some other non-specific diagnosis.



Fortunately, ten years ago when Dr. Harman felt the “oppressive force field” of PMR, he knew to seek treatment quickly because he had suffered his first bout of PMR seven years earlier. Dr. Harman’s experience underscores the point that PMR, like other forms of vasculitis, can go into complete remission with treatment, only to recur weeks, months, or sometimes even years later. Happily, low-dose prednisone worked as swiftly and miraculously for Dr. Harman’s second episode of PMR as the first. Indeed, a day or two after starting treatment, Dr. Harman reported that he felt so well that he could “leap tall buildings”. Perhaps even more impressively, he was able to resume all of his business and social activities. Eventually, Dr. Harman was able to stop the prednisone completely, an achievement enjoyed by only a minority of patients who suffer from PMR.

Over the last ten years, I’ve had the unique opportunity to discuss innovation and its importance with Dr. Harman, a man noted for his innovative approaches to business. We’ve discussed how creating and seizing new opportunities is crucial for success not only in business but also medical research. To put the lessons of innovation in context, let me give you some background about Dr. Harman’s business.

In the early 1950’s, Dr. Harman and Bernie Kardon formed one of the first high-fidelity sound system companies. For audiophiles, Harman/Kardon is a brand that represents superior sound quality, usability, and innovation. Chances are that the speakers in your stereo or computer were produced by a division of Harman International, the parent company to audio sound system brands of Harman/Kardon, Infinity, Mark Levinson, JBL, and Becker. Further, a few years ago, Dr. Harman saw that the information age offered the opportunity to develop systems that could revolutionize the way information and entertainment systems were built into automobiles. The same creative spirit that produced world-class car stereos led to the integration of a seamless electronics systems package for audio systems, monitoring appliances, and – most recently – global positioning satellite (“GPS”) map systems.

Not everyone saw the same opportunity. Indeed, one captain of the American automobile industry tried to dissuade Dr. Harman from pursuing this new direction. Paper maps, the auto executive noted, were plentiful and cheap, making it unlikely that anyone would ever pay to have GPS in a car. Dr. Harman thought otherwise. The information systems used by BMW, Mercedes Benz, Porsche and Audi are all manufactured by Dr. Harman’s company.

Dr. Harman’s latest success interests me greatly because innovation is equally important in medical research. As Chairman of the Department of Medicine at Johns Hopkins Bayview, I am always seeking new and better ways to help our faculty

provide care, conduct research, and teach our students. In future issues, I hope to describe in further detail the innovative program we are developing to bring together scientists from disciplines outside of rheumatology to advance our understanding of the genetics of Wegener’s Granulomatosis and other forms of vasculitis. In essence, we are trying to integrate different medical disciplines in the same way that Dr. Harman integrated the information systems found in the most advanced cars.

The value of innovation is only one of the many things I have learned from Dr. Harman. He has distilled many of his teachings into a best-selling autobiography, *Mind Your Own Business*. Reading the book may not make you a successful entrepreneur, but it will acquaint you with one of America’s most successful innovators.

Being a Professor at Johns Hopkins is great fun. While I can “profess” to know a few things, I am most excited about being a perpetual student and for having the opportunity to learn from my patients, including Dr. Sidney Harman.☀

*David B. Kellerman*

**JOHNS HOPKINS VASCULITIS CENTER**

**WEBSITE NEWS**

**OCTOBER 2004 — JANUARY 2005**

- Information on Rheumatoid Vasculitis
- Web Highlight Story: Linda’s Loop

**COMING SOON**

- Information on Methotrexate
- Information on Henoch-Schöenlein purpura

You can find us at:

<http://vasculitis.med.jhu.edu>

**The Rest of the Story:  
A Follow-up with David Standon**

We’ve gotten many queries about David Standon, a Vasculitis Center patient with Wegener’s granulomatosis whose story was described this time last year in the Winter 2004 issue of the Newsletter. Following a bug bite, Mr. Standon develop a tick-borne illness known as “human monocytic ehrlichiosis”, causing much diagnostic confusion in addition to profound heart dysfunction, landing him in the Critical Care Unit (CCU) at the Johns



**David Standon and his new grandson, Logan.**

Hopkins Bayview Medical Center.

We are pleased to report that Mr. Standon has made a complete recovery. Serial echocardiograms have shown that his heart function is normal again. With regard to his Wegener’s, Mr. Standon has also been fortunate: ANCA negative since April 2002, off all steroids for a couple of years, and now off azathioprine, too. He has decided to take early retirement from Verizon to devote more time to this passions in life: 1) fishing (“anything that swims”); 2) his wife, Chris; and, 3) his new grandson, Logan

To receive a copy of *The Johns Hopkins Vasculitis Center Newsletter*, please email your contact information to:  
[JHVC@jhmi.edu](mailto:JHVC@jhmi.edu).

## Patient Perspectives

### Winter Contributors: William and Melanie Kelly

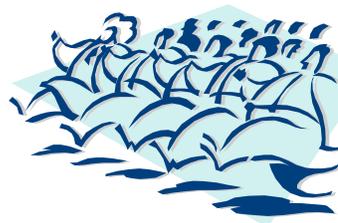
*Patient Perspectives* is a new feature in the newsletter that highlights vasculitis patient issues, our health care and our daily lives. If you have something you'd like to share about your experiences as a person living with vasculitis, please email Stacey LaBahn at [jhvc@jhmi.edu](mailto:jhvc@jhmi.edu) 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.*

### Going to Battle: One patient's strategies for winning the day, everyday

Mr. Kelly was diagnosed with Wegener's Granulomatosis in 1998. In caring for Mr. Kelly, first as a patient and then as a participant in a research study, those of us at the JHVC noticed how well Mr. Kelly's organizational skills helped him in coping with his illness and its complications. The JHVC asked Mr. Kelly if he would share his experience with our readers in his own words.



Since I have been afflicted with vasculitis and other maladies, I have had to come to terms with a new life style: medications, doctors' appointments, dietary alterations, and adjustments in quality of life. Not only does your lifestyle change when you have vasculitis; those of your family and loved ones may become altered radically, too. To manage the challenges of serious health problems, my solution was to come to terms with the new reality as quickly as possible. I knew I had to decide what I wanted to happen. When I first heard the news of the ailment, I experienced the five stages of grief: shock, disbelief, bewilderment, anger, and – finally – acceptance and resolution. The last phase, obviously, was criti-

cal; it helped me focus on controlling my health rather than allowing my health to control me. To move forward again and become healthy, I knew I needed a strategy. I started planning, which in many ways entails doing all the things that one might do in preparation for a battle. Here is my battle plan. (See opposite page for "Commander Kelly's Battle Plan.")

Melanie and I have lived "the word" of this "battle plan" and so we thought to provide a glimpse of how we have managed to live under the strenuous circumstances that have befallen us. I keep in mind that my maladies are my own and so it is my duty and my obligation to participate fully in the treatments prescribed by my doctors. That means do what they say to do and take the medications that they prescribe. In addition, I am obliged to speak up, to tell them when something that has been said or prescribed is not working, or it is causing pain or stress. Take responsibility, ask questions, and follow directions for your benefit. The more you know the better off you will be and improve the quality of your life.

The JHVC has posted on its website the medications chart and doctor/pharmacist list I've created for myself. (<http://resources/forms.html>). These documents can be saved to your computer and printed out for your own use. Ask a computer-savvy friend or family member if you need help. You can also ask for copies from the JHVC medical staff at your next appointment.☀

### *Can we be of service?*

Please email us at [JHVC@jhmi.edu](mailto:JHVC@jhmi.edu) or send your comments to:

**The Johns Hopkins Vasculitis Center**  
c/o Stacey LaBahn  
5501 Hopkins Bayview Circle  
JHAAC, Rm. 1B.1A  
Baltimore, MD 21224

## Medications

### Keep a simple medications chart:

- ◆ **A simple chart contains** your name, important contact information, a list of current medications that includes when you take them, how much you take, recent changes in normal dosage, and a list of any allergies.
- ◆ **Work to keep the chart as current as possible.** This will help you and the doctors “fine tune” the medications and track the effectiveness of new ones.
- ◆ **Post your medications chart on the refrigerator** or someplace else where you will be able to see it at a glance.
- ◆ For various **doctors’ visits, bring two copies of your medications chart** – one for you to write any changes on, the other for your doctor to keep. This will keep the doctors updated on your progress or changes.
- ◆ **Keep a copy of your medications chart with you** in your purse or wallet in case of emergency.

### Stay on top of your medications:

- ◆ If you take several medications, **use the little 7-chamber pillboxes**, one pillbox for each time of day that you take your pills. I take medicine *three* times per day, so I have *three* 7-day pillboxes marked morning, afternoon, and evening.
- ◆ **Fill the pillboxes every week on the same day** to decrease the risk of running out of a pill or failing to notice that you need a prescription renewal.
- ◆ **Adjust your refills to coincide with each other**, so that you only have to worry about refills periodically. Check with your pharmacist to know their “busy days” to avoid delays in refills.
- ◆ **Take your medications as instructed** by the pharmacist or the instructions that come with the medication. I learned to take my medications with meals after ingesting some food. This has helped me avoid getting an upset stomach.
- ◆ **Learn all you can about your medications.** Pharmacists can give you a printout on every medication you take. Read that information and understand it.
- ◆ **Know the medications side effects and preventative actions**, such as “sun sensitivity” or “take with food.” It is important so you know if you are experiencing a side effect, how to react, and when to call the doctor if that is warranted.

## Education

- ◆ **Learn all you can about your malady.** You may go on-line, ask your librarian, or find a support group for your disease. Your doctor can usually direct you to any of these groups or check the JHVC website at:

<http://vasculitis.med.jhu.edu/resources/links.html>.

## Doctors and Pharmacists

### Appointments:

- ◆ **Prepare for your appointment** by writing down any questions that have arisen during the period between visits.
- ◆ **Arrive 30 minutes before you are scheduled** to address any issues, (such as referrals, insurance issues, etc.) before being seen by the doctor.
- ◆ **Use a central appointment calendar for the household** to write down your appointments to prevent scheduling conflicts with members of the household.

### Orders & Instructions:

- ◆ **Make sure you understand your doctor’s instructions.** The key word is: understanding.
- ◆ **Ask as many questions as you need** in order to understand what your doctor wants you to do.
- ◆ **Write things down.** We don’t always remember even though it seems clear at the time!
- ◆ **Keep a running record of events with your medications chart.** Track unusual pains, improvements, reactions; any nuances that occur to help you remember those events.

### Medical Information:

- ◆ **Make a list of your doctors’ & pharmacies’ contact information**, such as names, addresses, specialty, phone numbers, fax, numbers, etc.
- ◆ Be sure that **your doctor has your permission through signed medical release forms to transfer your records** to any care provider necessary.
- ◆ **Ask about your medical records** so you feel confident all the information is present and correct. The medical staff can assist you in this process.
- ◆ If you wish, **keep track of your records** by asking doctor to note on the prescription or test requisition that you should be sent a copy of the report.

## Personal Health Maintenance

- ◆ **Exercise** is very important to your recovery and quality of life. Start out easy and increase as you can, until it feels right.
- ◆ **Diet** is about quality of life. Your doctor or dietician will help you define your diet. Ask questions! Your medical condition can control what your diet should be (as in my case).
- ◆ **Knowing your personal objectives and life’s direction** is important to regaining control of your life. Now is the time to set some realistic goals and to strive very deliberately to achieve them. ☀

**Ask the JHVC**

*Mrs. Gisela Heinz contacted the JHVC Newsletter office and asked... "Is there something special I should be doing with my diet or supplements?"*

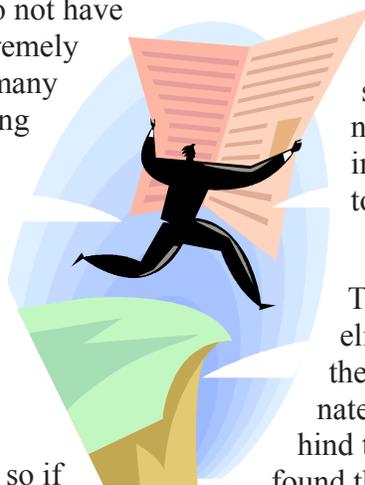
Two categories come immediately to mind when thinking about "diet" and "vasculitis"; they are **"Diet and Illness"** and **"Diet and Medications"**. For people with vasculitis, both categories have many important questions associated with them. In this issue, we'll take on the **"Diet and Illness"** perspective. In the Spring 2005 issue, we'll discuss **"Diet and Medication"**.

**Diet and Vasculitis—Part I: Diet and Illness**

**"They" say it works for arthritis. Would it work for me?**

A quick scan of the popular press while standing in the checkout line of a grocery store will reveal claims that certain foods are "miracle cures" for just about any challenging disease. Many immune-related diseases, such as systemic vasculitis or rheumatoid arthritis would fall in the category of a "challenging diseases" because they do not have cures; they are usually painful and extremely serious if not managed well. Finally, many people who suffer from them are looking for answers – hoping for relief.

As a "challenging disease" patient population, we are particularly vulnerable to cure claims because we want to believe something can "fix" it with the same speed and apparent ease with which the illness developed. We reason that vasculitis simply appeared, so if I do something simple, it will simply go away. At times, we are willing to try unproven claims in hopes that the newspaper articles are true. Claims state that by the elimination of certain foods or the consumption of specific supplements our medical problems will resolve themselves. In most cases this does not work, it can be very expensive, and – as we have seen with fen-fen, a once popular intermediary for weight loss – it can be dangerous to your health.

**Is there any harm in trying diet modifications?**

The lure of "it just might work" is very enticing; especially when it is something you can do yourself such as eliminating certain foods or taking a supplement. Our advice is to discuss any changes with your care providers. Many of us don't like to bring up "un-prescribed" health ideas with our doctors because we're afraid they will say, "No" or have a bias against something we'd like to try because it is unproven in the traditional medical community. But, the diet and supplement discussions with physicians are important.



Supplements, even those containing only natural elements, can change how medications impact your body. For example, some elevate the heart rate or restrict blood circulation. For diet changes, you should be especially cautious if your type of vasculitis has impacted major organs. Something as simple changing to a lower carbohydrate diet requires increasing protein intake. For a person who has kidney damage, it could be harmful to increase the quantity of protein consumed. If a change in diet is planned, a nephrologist or dietician who specializes in kidney disease would be the best person to discuss dietary adjustments.

The "diet change cures" claim that by eliminating certain foods you can eliminate the "triggers" of a disease, and thus eliminate pain or further flare up. The idea behind the elimination is that some people have found they are allergic to compounds in certain foods, and by removing the food you remove the irritant in the body. The idea is not completely unfounded, but controlled studies led by trained researchers dealing with food allergies and various immune system diseases have not been able to repeat consistent and qualified results, which leaves the outcomes highly questionable. No studies published in medical journals and publications have reliably shown diet adjustments as completely effective in controlling immune-related diseases.

### What should I do?

Before making modifications, it is always best to review the plan with a physician who understands all of your health issues before taking on a whole new way of eating or adding various supplements. If you are concerned about certain foods, removing them from your diet for an “assessment” period of time unlikely to cause no harm.



So, where does this leave us with the diets or supplements? Basically, we're back at Square One. Until we know more about vasculitis, specialty diets and supplements will remain anecdotal, at best. Research in vasculitis is gaining awareness by the organizations that sponsor it, and individuals are providing support to assist in research that will help discovery. It will be through research that answers will be provided along with advice on healthy diets and supplements that can assist in improving the health of patients with vasculitis.

On believing what we see and read in the popular news? Find out as much as you can about a diet or product before investing time, money and hope into it. Thorough research often turns up questions (and, possibly, concerns) based on your specific health issues. When it comes to eating certain foods do what is feels right to you, but as always, we advocate moderation and discussion with your care providers.



In summary, finding reliable information about managing unusual illnesses, such as vasculitis, is a challenging task for people not trained in medicine. The medical community is very sensitive to the need for good patient-centric medical information. They work to produce quality sources for the patients and family's who need it, but they also recognize how and where people find information is something they cannot control. So, a word to the wise, as stated in *Patient Perspectives* for Spring/Fall 2004, use your “common sense filter” when reading and learning about medical issues. Ask your vasculitis care team if you have any questions. ☼



Results of the **Wegener's Granulomatosis Etanercept Trial (WGET)**, coordinated at Hopkins, was published in *The New England Journal of Medicine* in

January. This trial, the first randomized, double-blind clinical trial of any therapy in Wegener's ever. It demonstrated unequivocally that – alas – etanercept is not effective in either the maintenance of disease remissions (or the induction of disease remissions when combined with conventional therapy). The search for a safe, effective medication for remission induction and maintenance continues. A copy of the WGET manuscript is available upon request by emailing [jhvc@jhmi.edu](mailto:jhvc@jhmi.edu).

**Dr. David Hellmann** was recently accorded two signal honors by the American College of Physicians (ACP). First, he was named a *Master of the ACP*, an acknowledgement of his numerous contributions to the field of internal medicine. Second, the Maryland chapter of the ACP named him the recipient of the *Theodore E. Woodward Award for Medical Education and Research*, given annually to recognize outstanding contributions as a teacher of medical students, residents, fellows and faculty.

**Dr. Philip Seo** led a multi-center study on the occurrence of damage in Wegener's granulomatosis. As the principal investigator leading vasculitis experts from nine medical centers, Dr. Seo described the contributions of both treatment and disease activity to the occurrence of patient morbidity, and drew attention to the need for a more universal approach to the assessment of damage in this disease. (See *An AVID Fan*, p. 8)

**Lourdes Sejismundo, RN, BSN** (*nee* Pinachos), Senior Research Coordinator, will be presenting “Biologic Therapies in Vasculitis” as an invited speaker at the Infusion Nurses Society annual conference for 2005. Also, Lourdes celebrated her marriage to Ian Sejismundo on November 27, 2004.

**Stacey LaBahn**, Communication Coordinator, contributed an article to the *American Medical Informatics Association Student Working Group Newsletter* about information, change and innovation. ☼

## An *AVID* Fan

Contributed by Dr. Philip Seo

I was not always a rheumatologist. For many years, I practiced general internal medicine. Therefore, I feel qualified to make the following statement:

*Doctors love pneumonia.*

It's not that we wish ill on anyone, but there is nothing quite as satisfying as diagnosing a patient with pneumonia. It is an example of basic medicine at its finest: generally, all you need to make the diagnosis is a stethoscope, maybe a microscope (if you want to get extra fancy), but, that's not the major reason that doctors love this diagnosis. We love pneumonia because — with timely diagnosis and the right treatment — everyone who has it gets better. After the coughing, the aches, and the shortness of breath have resolved, essentially no symptoms remain. Months later, when the former pneumonia patient returns for follow-up, there are no telltale signs to note how sick he or she was. Basically, a pneumonia patient returns to normal with few, if any, detectable scars and not long-term consequences.

Not so with vasculitis. Even when identified and treated appropriately, vasculitides often leave behind evidence of their passage. Diseases, such as Wegener's granulomatosis, Takayasu's arteritis and Polyarteritis nodosa, are like a fire in a burning



CAT scan of patient's lungs, showing a normal lung (image: right) and an abnormal one (image: left identified with red circle). The abnormal lung is shrunken primarily required to make the Wegener's diagnosis.

house. In a building, the heat and the flames get our attention at first, but it is frequently dealing with the fire's aftermath—the soot marks on the walls, the water damage, the charred foundations—that pose the most

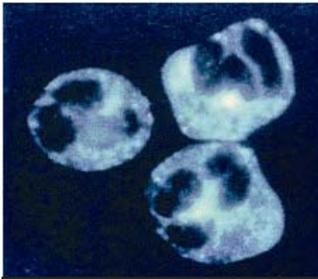
challenging problems. The same holds true for vasculitis.

In general, vasculitis can almost be thought of as two different diseases. There is the acute disease (the actual fire in our house fire), known by the muscle aches, the joint pain, the fever, or the rash that precedes a vasculitis flare. But there is also the chronic disease, the kidney problems, the trouble breathing, the weight gain, and the muscle loss that occurs and persists, even when the disease is no longer active. These symptoms are the residuals like the soot, water mark, and foundational destruction of the house fire. These changes are the consequences of vasculitis and are called *damage*.

*Damage* is usually considered to be the result of active vasculitis. As vasculitis patients know, however, *damage* can also be a consequence of treatment. When researchers study new medications, we evaluate the ability of new medications to limit *damage*. Because of the variations in each type of vasculitis, this is more difficult than you might think. Without doubt, the medications we use to treat active vasculitis save lives, but no medication is completely without potential consequences. When we select medications, our goal is always to minimize the possible adverse effects. So, like our house on fire, we work to choose the appropriate extinguisher based on the type and size of the fire, trying to keep as much of the structure undamaged as possible. Doing this requires an understanding the composition of each fire, like the differences between a grease fire or a wood fire, and what best puts it out, baking soda or water. It requires a guide that defines the problems and what will happen with different diagnoses.

One of my research interests at the Vasculitis Center is to study and build a "dictionary" of *damage* in vasculitis caused by active disease, chronic disease, and treatments. The ANCA-associated Vasculitis Index of Damage (*AVID*) catalogs the common list of problems that are acknowledged widely to be a consequence of vasculitis or the medications used to treat vasculitis.

As people concerned with vasculitis, you know there are many forms of vasculitis and many treatments, as well. The combination of disease and medication factors lead to an almost unpredictable number of consequences. *AVID*, a multi-center effort involving medical sites in both the United States and Europe, focuses on analyzing ANCA-



White blood cells “lighting up” because of antibodies to proteinase-3, causing an C-ANCA pattern

associated vasculitides, such as Wegener’s granulomatosis, Microscopic polyangiitis and Churg-Strauss syndrome.

Through targeting ANCA-associated disease, other vasculitides will benefit from the damage analysis index because of the similarity in treatment and the uniformity in vasculitis research terminology it pro-

vides.

The *AVID* is a crucial step in vasculitis research. All diseases need a common vocabulary with definitions agreed by the scientists and researchers who study them. Currently, the global community performing vasculitis research each has a unique set of experiences and biases leading to independent definitions. *AVID* will provide to vasculitis researchers a common lexicon with which to define, predict, and prevent damage associated with disease and treatment.

In treating vasculitis, modern therapies have been enormously successful in improving the *quantity* of life enjoyed by patients. Our next challenge is to improve potential *quality of life* as well. Studying damage associated with vasculitis is important because we know that living is not enough. We also want you to live *well*.☀

**KNOW YOUR MEDICATIONS: BACTRIM**

Contributed by Matt Marriot, PAC, MS

**What Is Bactrim?** Bactrim is a medication that is used to treat infections. The generic name of the medication is trimethoprim/sulfamethoxazole (TMP/SMZ). It is also commonly used in our Center to prevent the occurrence of infections. Bactrim is a sulfa-based antibiotic. Therefore, if you are allergic to sulfa-based drugs, you should not take this medication.

**Why do I have to take an antibiotic?** Patients with vasculitis are frequently treated with cyclophosphamide (cytoxin), high doses of prednisone, and other drugs that suppress the immune system. These medications may make you more susceptible to certain types of infection. Among these infections is *Pneumocystis pneumonia* (PCP). Taking a low dose of Bactrim on a regular basis is an effective way of preventing this infection.

**How long do I need to take this antibiotic?** Most antibiotics are taken for a limited amount of time to treat a disease or infection that you already have. But for vasculitis patients, Bactrim is used to prevent certain types of infection. Regardless of how you feel, you need to take it on a regular basis. Bactrim may become a part of your routine medications for a year or longer, depending on your disease status and other considerations.



Normal dose for vasculitis patients is single strength or 80/400mg weight

**What are the possible side effects?** Common side effects include rash, hives, nausea or vomiting

**What if I am already taking an antibiotic?** Bactrim’s ability to prevent PCP is unusual among antibiotics. Most other antibiotics do not have these properties. Even if your doctor prescribes another antibiotic, you should continue to take Bactrim unless instructed otherwise.

**Why should I risk a possible allergic reaction?** Allergic reactions to sulfa-based medications are not uncommon. Most, fortunately, are mild. Because of this potential for allergic reactions, we prescribe Bactrim at the lowest effective dose, and stop it as soon as it is safe to do so. If you believe you are having an allergic reaction to this medication, you should notify us or your primary care provider immediately.

**Does Bactrim effect dialysis?**

Patients receiving dialysis may require less Bactrim than those with normal renal function. If you are receiving dialysis, your physician may decide to decrease your Bactrim dosage, although dosage adjustment is not always necessary.

**Should I be on Bactrim if I am pregnant or nursing?**

No. Bactrim can cross the placenta and can be found in breast milk. Therefore, if you are actively nursing, or planning on starting a family, please let your physician know.☀



## Clinic Corner: New Clinical Trial for ANCA-Associated Vasculitis

### Inside this Issue:

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We are seeking patients with active Wegener's Granulomatosis or Microscopic Polyangiitis for an international clinical trial designed to assess whether a new antibody therapy can induce remission of disease. The antibody, known as "rituximab," targets specialized immune cells called B cells. The treatment has shown promising results in preliminary studies, including a recent publication in *Arthritis & Rheumatism*.

Eligible patients must be 15 years of age or older with active Wegener's Granulomatosis or Microscopic Polyangiitis. Participants will be randomized to receive either rituximab (the investigational drug) or cyclophosphamide (Cytoxan) therapy, in addition to standard maintenance therapies. Participation will continue

for 18 months following initial treatment, with several study visits required. Crossover to the other treatment arm is possible for patients who fare poorly with their initial treatment assignment. Compensation is available for participating patients.

If you believe you are eligible for this study and may wish to participate, ask your healthcare provider to contact study investigators for more information. To learn more about this trial, please e-mail the Vasculitis Center at [jhvc@jhmi.edu](mailto:jhvc@jhmi.edu), view our site at <http://vasculitis.med.jhu.edu>, or check out the webpage of the trial sponsor, the National Institutes of Health's Immune Tolerance Network: <http://www.immunetolerance.org/RAVE>. ☼

HTTP://VASCULITIS.MED.JHU.EDU

WE'RE ON THE WEB!

Research Office Telephone: (410) 550-6816

Scheduling Telephone: (410) 550-6825

JHAAC, Suite 1B.1A

5501 Hopkins Bayview Circle

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