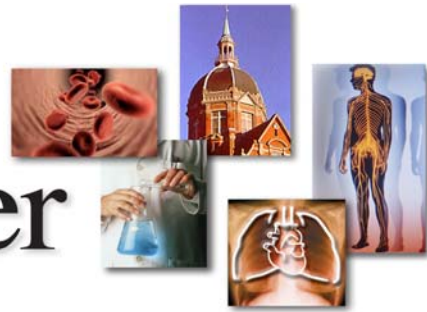


THE JOHNS HOPKINS Vasculitis Center



LIFE IS FOR GIVING

BY JOHN STONE, MD, MPH AND SEEMA AGARWAL-HARDING

INSIDE THIS ISSUE:

Life is for Giving	1
Patient Perspectives: Working toward Finding a Sense of Purpose	4
A Question to the JHVC: Diet and Medication	6
Mycophenolate Mofetil (CellCept)	7
Proteomics for Poets	8
Know your Medications: Erythropoietin	9
JHVC in the News	10
Clinic Corner	12

New Newsletter Design

The JHVC has a new logo and look! To share your thoughts, email us at JHVC@jhmi.edu or write to us at the address found on page 5.

Stacey LaBahn
Communication Coordinator

The JHVC Newsletter for 2005 is generously sponsored by an educational grant from Mr. Christos Lambrakis.

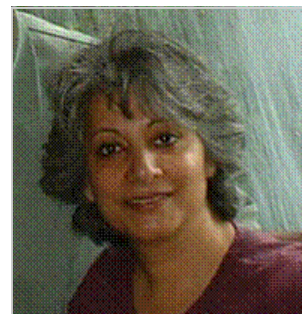
Sometimes the best part of our job at the Johns Hopkins Vasculitis Center is telling patients that they don't have vasculitis. This was the case with Seema Agarwal-Harding, a woman whom we were asked to evaluate for possible Takayasu's arteritis.

In the autumn of 2004, Mrs. Agarwal-Harding, a senior official in the United States Agency for International Development (USAID), suffered a stroke while on assignment in India, the country of her birth. Following an extensive evaluation in New Dehli, she made her way to Hopkins. The possibility of vasculitis was raised and, indeed, some evidence suggested Takayasu's arteritis. Mrs. Harding is Asian, a woman, and younger than 50. She had no prior vascular problems and had demonstrable arterial abnormalities on a angiogram of her brain.

*A Rheumatology consultation led to a visit to the Vasculitis Center, where the diagnosis of Takayasu's was excluded. The radiological findings bore all the hallmarks of another diagnosis, **fibromuscular dysplasia**, a non-inflammatory disorder that frequently involves the arteries to the kidneys and (sometimes) those of the brain. Distinguishing Mrs. Agarwal-Harding's illness from Takayasu's was critical. The treatment of fibromuscular dysplasia differs drastically from*

that of vasculitis. (See inset on page 2)

Our opportunity to assist Mrs. Agarwal-Harding, a thoughtful, gracious, and articulate woman, could not have been more of a pleasure. Early this year, she wrote to me about her recovery progress. Struck by the sensitivity of her writing, I



Mrs. Seema Agarwal-Harding, USAID Senior Education Advisor-Near East Asia, wife, mother, and humanitarian.

asked her permission to re-print an excerpt of her recollections. As a relief worker who has spent her career at USAID (and much of that time in Asia), her reflections on her own illness are colored

by an unforgettable world tragedy that occurred while she was recovering: the Tsunami that devastated large parts of Asia in December 2004. Part of Mrs. Agarwal-Harding's frustration with her own illness was her inability to help directly with the Tsunami relief.

All too often, medical illnesses – particularly vasculitis – hit with the apparent suddenness and, certainly, the individual devastation of a Tsunami. Mrs. Agarwal-Harding's story points to the power

Takayasu's arteritis compared with Fibromuscular dysplasia

In contrast to Takayasu's arteritis, fibromuscular dysplasia (FMD) does not respond to prednisone. But like Takayasu's, however, fibromuscular dysplasia requires careful follow-up with serial imaging studies. If there is evidence of worsening of the arterial problems, FMD is amenable to "revascularization" procedures such as balloon angioplasty or stent placement.

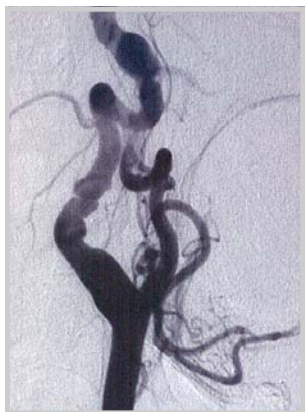


Image courtesy of Seema Harding

Typical FMD MRI

Rather than showing smooth linings of the blood vessel walls, fibromuscular dysplasia is characterized by kinked, torturous vessels that sometimes resemble stacks of coins.

LIFE IS FOR GIVING (CONTINUED)

of "our better angels", whom we attempt to summon in the practice of medicine.

October 27, 2004. 5:05 p.m. - New Delhi, India. The story of my second life began in the catastrophic first moments when I collapsed at the Indira Gandhi National Airport. How this story will end I still do not know, but my close brush with death on that day has taught me much about life, its purpose, and the goodness in people. My story is one of affirmation of love for the human spirit – the common good that unites us as people – and inspires me with courage and hope for my own life and work. Kathy, my friend, calls it: being "touched by an angel". Corny though it sounds, I wish that everyone might gain a sense of what it is like to have such an enriching, life-saving experience.

Dr. Dana Fischer, a USAID Director and co-worker based in India, was the first angel who, in those first critical days of my stroke, had the presence of mind and the heart to save my life. She guided me through the horrifying confusion of the event and its aftermath, negotiating my path through the Indian health care system when it seemed my life was being swept away. Many more angels have appeared since, few of whom I knew before my catastrophic moment at Delhi airport. But something connected us - our common human spirit. These angels had, and

still have, the same capacity for love and giving to others that inspires my personal and professional life. It is this power that sustains our world. It is life and positive energy. That is what has given me my second life.

Since then - in fact, two months later after my own crisis - the world faced a terrible tragedy on December 26th, 2004. A Tsunami hit the coasts of Indonesia, Thailand, Sri Lanka, and India, killing almost 150,000 people in the course of a week. Even now, months later, the world has yet to recover fully. How can one begin to fathom such loss? My personal crisis pales in the wake of such a gargantuan disaster, with unspeakable consequences for individuals, families, whole societies, and entire cultures. In addition to the horror of the Tsunami and its aftermath, as I hear and read in the media about this and other world events, I am struck daily by how divisive we can become. Rather than focus on what unites us, we have become obsessed with our differences, with creating divisions between and among us, for ambition, power, and gain. We see and hear examples of this each night on the Evening News.

Recently, as I listened to former Presidents' George Bush, Sr. and Bill Clinton talk about the Tsunami Relief efforts, public-private alliances, and the need to focus on "the right way", I was reminded of my own conviction in the power of the unifying way as "the right way"; the one that brings out our common humanity and the desire to preserve and nurture it.

LIFE IS FOR GIVING (CONCLUSION)

Whatever one's cultural, social or religious affiliation, people have similar ways of responding to tragedy and loss, and the needs of those we love. It is the search for that "common good" that inspires people. I first experienced this in my life years ago when I was working as Chief of Education programs for UNICEF in Ghana. I started a child-centered community school project in a remote rural part of Ghana. Some years later, when I designed the Community-Schools project for the United Nations in India – these "Education for All" projects goal was to secure children's well-being; a focal point that would catalyze parents, educators, government workers, and policy-makers. The projects start with the child, and focus on the child's basic needs for education, safety, and health, building her and his capacity to reach full potential. The books, teacher training, the policies, exams, became tools to support the child's needs. In the Afram Plains, Ghana, and eight states across India, we united people's efforts around fulfilling the child's physical, emotional, and intellectual needs through basic education programs. The local impact of these programs have been enormous.

Today, in my current capacity as Senior Education Advisor for USAID's Asia Near East Bureau, I am attempting to build a program with similar impact for disenfranchised youth in several countries of the region. Our Education and Employment Alliance involves educators, families, communities, policy-

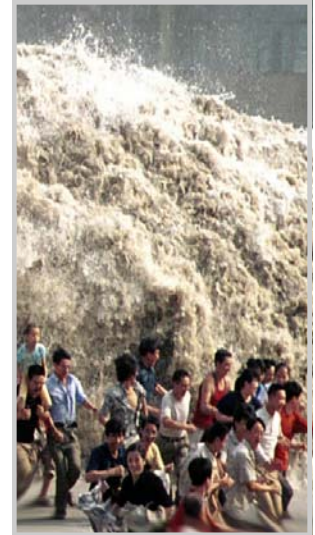
makers, and the private sector with one purpose and common objective: to provide hope and work for hundreds of disconnected youth through enhanced education and skills development programs.

As I recover from my subarachnoid hemorrhage, multiple strokes, occluded left vertebral artery, left cerebellar infarct, clot in my right brachial artery, chest pain, and deep venous thrombosis, all symptoms of this rare disease for which physicians at John Hopkins are still treating me, I feel lucky. Lucky because I feel more alive today than I have for years and more convinced that the unifying way is "the right way". My experience has strengthened my conviction that it is our common humanity and unity in diversity that saves lives, nurtures and sustains goodness, growth, and prosperity for all. After all, I wouldn't even be here to tell you this story, were it not for the many angels and unforeseen acts of goodness and support that helped me to survive. ☀

Seema Agarwal-Harding

Dedication

This article is dedicated to the victims and survivors of the Tsunami disaster, and to the spirit of "Loksamgraha" – a Sanskrit word meaning the "Good of all".



People caught off-guard while wave watching during Tsunami of December 2004. The water is coming over a retaining wall.

Photo provided by: Dr. Suk Chyn



Unswayed by the dangers, people wading and wave watching with only umbrellas to protect them. (Tsunami, December 2004)

Photo provided by: Dr. Suk Chyn Gun



Seema with her husband, David, and their son, Kiran, and daughter, Priya, on a family trip to Costa Rica.

PATIENT PERSPECTIVES: WORKING TOWARD FINDING A NEW SENSE OF PURPOSE

BY CAROLE STUDDARD

Inspiring Thoughts

“Be of good cheer. Do not think of today’s failures, but of the successes that may come tomorrow. You have set yourself a difficult task, but you will succeed if you persevere; and you will find a joy in overcoming obstacles. Remember, no effort that we make to attain something beautiful will ever be lost.”

Helen Keller



“Chronic illness will bring peaks and valleys; the valleys will come but they make the peaks that much more enjoyable, to be grateful for and to be passed along.”

Greg Studdard,

My son’s thoughts on dealing with chronic illness

Carole’s Reading List

Here are a few books Carole found thought-provoking, helpful, and inspiring.

At the Will of the Body
by Arthur W. Frank

Living Between Office Visits
by Bernie Seigel, M. D.

Climbing Higher
by Montel Williams

Recently, I saw the call for volunteers in The Johns Hopkins Vasculitis Newsletter. By volunteering, I hoped to take another step toward something I had lost: a sense of purpose. Though I had significant health challenges prior to being diagnosed with Takayasu’s arteritis, this rare and difficult to diagnose disease mandated drastic changes in my life. With this said, I would like to share some personal thoughts that may be helpful to others on working toward finding a new sense of purpose after the diagnosis of vasculitis.

What do you do when everything changes?

I have been a very active person all of my life. I raised children, and had a gratifying professional life from owning my own business to working for a large corporation with great, supportive people. In 2002, my life changed due to Takayasu’s arteritis. I found myself facing a disease that caused my identity, or my perception of it, to disappear suddenly.

All of us with vasculitis grapple with trying to understand this disease and its profound impact on our lives. Some people struggle with how to care for children while others lose the benefit of a job and the income on which they depend. Most people find their energy and lifestyle drastically changed. The scope of life shifts from a productive, active lifestyle including being gainfully employed, helping and supporting others to dealing with a disease that takes its toll physically, mentally, emotionally,

and spiritually. How do we deal with that? Who are we now?

Managing me

When I first started having medical issues several years before the diagnosis of Takayasu’s was made, my local rheumatologist shared a critical point with me. She said, “Your job for the next couple of years is to take care of your health.” At the time, I thought I could “fix” everything quickly with a few

modifications in my lifestyle. It has taken me years to realize that the practitioner was right: for a period of time, my health needed to be my “job.”



Carole Studdard and her husband, Gary.

Making my healthy job required

much of the energy I had formerly put into my family and work to be redirected towards me — not a comfortable place when you are used to providing support. It required breaking down some personal stereotypes. Focusing on myself was very new. At first, it seemed selfish. Talking to people about my good and bad days felt like whining, which I have always shunned. I had to redefine that putting my health first was not selfish, but rather *self-preserving* and discussing what was happening to me with family and friends was not whining, but simply being open about how I was doing.

There is a balance, though. The people in our lives love and care for us, but even they have their own issues to deal with beyond us. Chronic disease does not mean that the world should focus

PATIENT PERSPECTIVES (CONCLUSION)

solely on us. The balance is knowing my disease is not all about me, and that if I take care of myself, it will give me a future to be there for my loved ones. Once I understood and internalized this, I unknowingly took my first step towards a new sense of purpose. By stabilizing my health, I could be well enough to look outside myself again.

Reaching out to the outside world

The next step in my journey towards a sense of purpose was reaching out to the world again. Despite our personal challenges, I believe we need to look at the positive parts of our lives and commit to doing whatever we can do be-



yond ourselves. There are days when it seems easiest to just keep my head on the pillow, not spend time with friends, not answer the phone: just to lie low. But there is nothing to be gained by these inactions. Trust me! Nothing has been more helpful for me than putting behind my “pity party” and returning to the world beyond my own challenges. Contributing to my family, city, religious community, and neighborhood has given me a sense of balance. Until recently, I never realized how much value I have to give until I reached out to others. I am no longer fully employed nor am I able to do everything I could do before, but I do have time to share and that is gratifying. It has, once again, given me a sense of usefulness that I felt I had lost.

In respect to my first step -- managing me -- I do have to be careful not to overdo it and to realize that vasculitis can limit my energy. It’s about putting priorities in place to manage our lives. There continue to be the day-to-day tasks we all need to do, but when you do your best to schedule reaching out to others, your sense of worth and purpose will rebound and you will find joy and happiness once again.

Today

Today, I am grateful to be a patient of the Johns Hopkins Vasculitis Center, where I have been treated for almost two years. Recently, my disease has become active again, which I have learned is not uncommon. I will do my best to overcome this challenge. At times, I continue to be sad and disappointed that I was unable to make the necessary life changes prior to my Takayasu’s diagnosis. For had this happened, it is possible the disease wouldn’t have progressed to the degree it did. But I am more comfortable with this than I was a year ago, or even only several months ago. Life continues to be a journey to find a new sense of purpose. At times, I still feel anger and frustration about such sudden changes, mostly due to the impact it has on those whom I care about and love, but I know if I “do my homework” I’ll find sure footing on the path to purpose. My goal is to do my best to live as a healthy person with goals and not a person with an illness. ☀

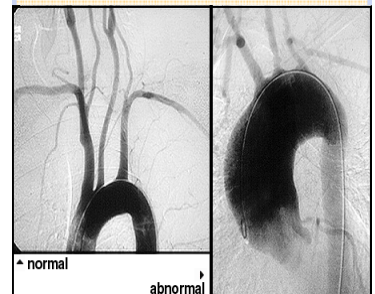
Can we be of service?

Please email us at JHVC@jhmi.edu or send your comments to:

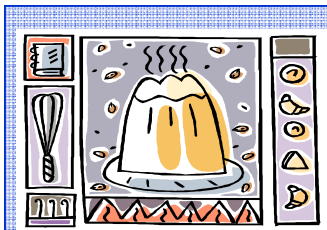
The Johns Hopkins Vasculitis Center
c/o Stacey LaBahn
5501 Hopkins Bayview Circle
JHAAC, Rm. 1B.1A
Baltimore, MD 21224

Takayasu’s Arteritis

is an inflammatory condition that affects the largest blood vessel in the body (the aorta) and its branches. The complications of Takayasu’s arise directly or indirectly from damage to this major blood vessel. Clinicians divide Takayasu’s arteritis into two phases: 1) a **systemic** phase; and 2) an **occlusive** phase.

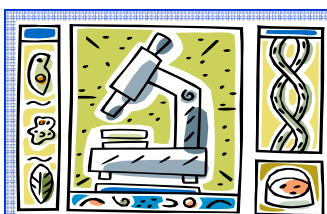


In the **systemic phase**, patients have symptoms and signs of an active inflammatory illness. These may include “constitutional symptoms” (fever, fatigue, weight loss), arthritis, and non-specific aches and pains. The systemic phase is followed by the **occlusive phase**, during which patients begin to develop symptoms caused by the narrowing of affected arteries. These may include pain in the arms or legs that occurs during repetitive activities, such as brushing hair or walking. During the occlusive phase, affected blood vessels may become narrowed so that the pulses of the arms or legs are no longer palpable; hence, the disease’s other name is the “pulseless disease.”



What are “refined carbohydrates”?

Processed foods, made with white flour, white rice, sugar, and white flour pasta, for example, often cause swings in blood sugar levels. As replacements for processed foods, complex carbohydrates found in fibrous green vegetables and whole grains are recommended. Studies have also shown that increasing protein, preferably “lean” protein such as fish, chicken, tofu and other soy products, reduces the frequent “hunger” so commonly affiliated with taking prednisone.



Information Sources

See our Resources on the JHVC website at <http://vasculitis.med.jhu.edu/resources/links.html>. There you'll find links to information on Type II diabetes by the American Diabetes Association and bone health by the National Osteoporosis Foundation.

ASK THE JHVC: MEDICATION AND DIET

BY STACEY LABAHN

Mrs. Gisela Heinz contacted the JHVC Newsletter office and asked... “Is there something special I should be doing with my diet or supplements?” Winter 2005

Diet and Vasculitis: Part II Diet and Medication

As the medication pamphlets from pharmacist’s note, the medications taken for vasculitis have potentially strong side effects. Prednisone may cause weight gain and bone problems - osteoporosis (bone thinning) and osteonecrosis (bone death). Worries of infection, organ damage, or cancers are a part of taking certain other immunosuppressants, such as azathioprine (Imuran), cyclophosphamide (Cytoxan), or methotrexate. Preventative measures can help reduce these risks and side effects.

Weight gain or loss

Prednisone is the primary culprit in weight gain. The drug slows metabolism, encouraging weight gain and increases blood sugar, which causes that “always hungry” feeling. In other words, prednisone induces type II diabetes. According to the American Diabetes Association (ADA), type II diabetes is controlled by diet through reducing the amount of refined carbohydrate eaten. As nutritionists’ research the potential health impacts of a reduced carbohydrate diet, many of the studies show that people with low metabolism and increased blood sugar (such as those on prednisone) can benefit from reducing refined carbohydrates and increasing lean protein in their diet.

Bone health

Two possible skeletal side effects of prednisone are osteoporosis, which is a thinning of the bones, and avascular necrosis (AVN) which means bone death. These disorders are monitored through

bone density measurements, MRI studies and CT scans. The best preventative for bone health is adding a combination of calcium, magnesium, and vitamin D to your diet. If additional medicinal support is necessary, new medications that encourage bone re-growth and detour calcium depletion are available.

Infection

When taking immunosuppressive medication, risks of infection and illness increase because the body’s defenses are impeded by the very medications designed to control the hyperactivity in the immune system. To help fight colds and the flu, some studies imply that vitamin C and zinc can help. Definitive proof of these effects, however, remain in short supply. Another health risk to watch is improperly cooked foods (undercooked or mishandled) or raw foods, such as sushi, oysters or tartar/carpaccio (thinly sliced raw meats). It is best to avoid these types of food preparation.

Organ damage or cancers

Immunosuppressants are hard on the body. They can build up in organs causing damage, or at their worst, cancer. The best preventative for the health of your organs is to drink plenty of water. Water helps flush the toxicities from your system.

A word of caution: If you experience kidney problems due to vasculitis, please consult your nephrologists before increasing fluids or protein in your diet.

Those of us with vasculitis are faced with the choice: taking medications that risk side effects or not taking them and risk the ravages of vasculitis. Most will take the risk of medications and apply preventative management to reduce the effects. For prevention, diet or vitamin supplements can be used wisely in order to help reduce the seriousness of these side effects. ☼

MYCOPHENOLATE MOFETIL (CELLCEPT)

BY MATTHEW MARRIOTT, PA-C AND PHILIP SEO, MD

Autoimmune diseases such as vasculitis all share a common characteristic, in each case, the immune system has made a mistake. Many of the cells in your bloodstream are designed to fight off infection. Once in a while, these cells attack the body instead, leading to autoimmune diseases such as thyroiditis, multiple sclerosis, or vasculitis.

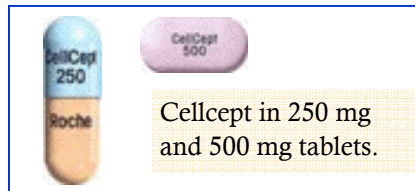
Treatment of autoimmune diseases such as vasculitis, generally focus on “suppressing” your immune system just enough so that the body stops attacking itself. Corticosteroids (prednisone) are the most potent immunosuppressant medications we have and frequently form the cornerstone of treatment.

Unfortunately, steroids are associated with a wide range of side effects, so we continue to look for “steroid-sparing agents” to use in place of prednisone once the vasculitis is under control. Mycophenolate mofetil (MMF), commonly known as CellCept, is an example of “steroid-sparing” medication. The following information are based on common concerns asked when prescribing CellCept to vasculitis patients.

How does MMF work? Lymphocytes are important type of cell in your immune system. Lymphocytes should attack foreign bodies, like bacteria or viruses, but in patients with autoimmune disease (such as vasculitis), they attack the body itself; a.k.a .the wrong target. MMF helps bring autoimmune disease under control by decreasing the number of lymphocytes in your blood. MMF is called a “specific inhibitor” of lymphocytes, mean-

ing that it rarely affects other types of cells, particularly at the doses used with vasculitis patients.

How long will it take MMF to work? MMF starts to affect your immune system soon after it is administered, but it may be months before we can measure its true effectiveness. The delay occurs because the dosage needs to build up over time. We find that if we start at the lower doses at first, it is better tolerated physically and has fewer side effects.



What are common side-effects of MMF? Gastrointestinal side-effects such as nausea, diarrhea, and abdominal cramping are the most common. Generally, these symptoms are not dangerous, but they can be a nuisance and are most often the reason patients stop taking CellCept. If you develop gastrointestinal symptoms, we may lower the dose for a period of time or divide the total daily dose into smaller doses throughout the day. Small doses of MMF at frequent intervals are well tolerated,. Trying this for a short period of time may help your body time to adjust to the new drug.

How well does MMF work? For patients with Wegener’s granulomatosis, MMF has been shown to be both safe and effective. One study suggests it may be effective for maintaining disease remission in some patients. There is less ex-

perience using MMF for the treatment of other diseases, although we commonly use it for the treatment of microscopic polyangiitis, Takayasu’s arteritis, and vasculitis that affects the skin.

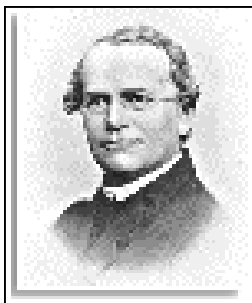
How often do I need to be monitored? Blood work is initially required every two to four weeks to ensure that your body is tolerating the medication. The interval can then be increased to once every one to two months. Our practice is to decrease your dose of CellCept if your white blood cell count falls below 3500/mm³. Additional blood work may be needed to follow disease activity, response to therapy, or the presence of infection.

Can I take MMF if I have kidney disease? Yes, although patients with end-stage renal disease receiving hemodialysis or peritoneal dialysis may require a reduced dose. Patients with kidney problems may have more difficulties with side-effects, but not always.

Are there any other precautions I need to take? MMF should not be taken with antacids or iron supplements, both of which may impair your body’s ability to absorb the medication. As with most immunosuppressive medications, you should not take live attenuated vaccines such as measles, mumps, or rubella. You should, however, continue to have an influenza vaccine every year and a pneumococcal vaccine once every ten years. Finally, MMF can cause problems with pregnancy and, for that reason, we ask all women to use effective forms of contraception while taking this medicine.☀

PROTEOMICS FOR POETS: A PRIMER FOR THE CONFUSED

BY PHILIP SEO, MD



In the 19th century, Gregor Mendel elegantly demonstrated the concept of genes by showing how a plant

inherits—in equal measure—a combination of traits from its mother and father. Long before we understood what makes a gene, this insight formed the basis of the entire field of genetics. Despite Mendel's ground breaking work, a central question remained: no one understood how such a large amount of complex information could be transmitted from generation to generation.



In the 1950s, Francis Crick and J. D. Watson demonstrated that deoxyribonucleic acid (better known as DNA) is the stuff of life. The miracle of DNA lies in its ability to record enormous quantities of information within the smallest spaces, allowing a child to inherit a mother's smile or a father's chin. Subsequent research rapidly demonstrated how DNA could transmit its message throughout the cell to organize the formation of proteins, which are the building blocks of all forms of life.

Anyone who has sat through a high-school biology class has heard the Central Dogma: DNA makes RNA. RNA makes protein. Although it sounds pretty basic, those six words capture the essence of the revolution in molecular biology that started in the last century, and continues into the modern era.

In retrospect, the Central Dogma is correct, but it only touches on a small aspect of how life works. The Era of the Acquired Immunodeficiency Syndrome (AIDS), for example, has shown us that not all forms of life use DNA to transmit their genetic code. The human immunodeficiency virus (HIV) uses ribonucleic acid (RNA) to store its genetic information. Odder still is Bovine Spongiform Encephalopathy (better known to most of you as "Mad Cow Disease"), which uses protein to store genetic information, a quirk that makes this infection unusually difficult to eradicate.

Even the most straightforward cases are not all that straightforward. In some estimates, only 10% of the genetic code actually transmits useful information. It is as if you were handed a novel to read, but were warned that only one out of every ten sentences is rele-

vant to the plot. Even if we were always able to figure out which parts of the genetic code were important, the mystery does not stop there. Figuring out how the individual proteins are glued together is just as important as finding out which proteins are being used.

This is why the field of proteomics has become so important. The study of genes, through genetic engineering, has led to enormous advances in the 20th century, yet is inherently limited because it analyzes genes string by string. This would be similar to learning a new language by carefully studying a handful of words. Proteomics uses the opposite approach, examining the combinations of proteins found in our bodies to determine what makes life possible. Many diseases may be caused by a mistake in the proteins our bodies produce with too much of one thing or too little of another making bad combinations. By examining these mistakes, we may be able to make fundamental discoveries in the pathogenesis of disease that would otherwise be impossible to identify.

It probably goes without saying that if this were easy, it would have already been done by someone else. If genetics is like learning English by studying a dictionary, then proteomics is a little like learning English by studying Shakespeare. Proteomics allows us to start with the full sentences; it is then up to us to figure out the individual words, and more importantly, how those words combine to create meaning.

PROTEOMICS (CONT'D)

Proteomics is generally a two-step process. In the first step, we take a blood sample (or a small sample of the diseased organ) and we isolate all the proteins we can. We take those proteins and shatter them into many pieces. In general, proteins will shatter in a characteristic pattern, giving us a “fingerprint” that we can use to track down the identity of the original proteins. This second step is typically the most challenging. It is also the most rewarding, because it allows us to skip all of the guesswork involved in determining which genes might be relevant to a particular disease. This allows us to focus on the proteins that have a good chance of being important.



We are all more than the sum of our parts. Each one of us is a complex tale—written in words made up of proteins—which combine in specific and complex ways to tell the stories of our lives. Proteomics allows us to read those stories. It is a particularly exciting field for those of us who study vasculitis because we know (better than most) that not all stories turn out as well as we would like. We all hope that someday, if we read the proteins very carefully, we will learn how to write some stories of our own so that everyone can have a happy ending.☀

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Mendel: ©Access Excellence @ the National Health Museum

Crick and Watson: © Corbis Images

KNOW YOUR MEDICATIONS: ERYTHROPOIETIN

By DR. DURURU GEETHA

What is erythropoietin?

Erythropoietin (EPO) is a naturally occurring hormone produced by the kidneys that stimulates cells in the bone marrow to produce new red blood cells. Red blood cells are needed to carry oxygen to cells, tissues, and organs in the body. A lack of red blood cells is called anemia. Epogen, Procrit, and Aranesp are man-made copies of human erythropoietin.



Why do I have to take EPO?

When an EPO deficiency causes anemia, patients commonly experience fatigue caused by the anemia. Other reasons, such as possible heart problems, sexual dysfunction in men, menstrual disruption in women, and slowed growth in children are reasons to boost red blood cell counts.

Is EPO used to treat all types of anemia?

No. EPO is mostly used in patients with kidney failure, for treating cancer patients on chemotherapy, or patients with HIV.

Why is anemia common in people with chronic kidney disease?

In patients with chronic kidney disease, it is common that the kidneys cannot produce enough EPO.

How is EPO given?

It is generally given as an injection, administered during dialysis treatment or into the skin. You can be taught to give the injection or a nurse can give it to you.

How often do I take EPO?

Depending on your blood count, it

can be taken as up to three times a week or as seldom as every other week.

How do I know if EPO is working?

Your doctor will monitor your blood count to see if it is working. EPO may not work if you have iron deficiency (usually people are given iron with the EPO) or if there is infection or inflammation.

What are the side effects?

The side effects are rare, but each person is different. The common side effects reported include flu – like symptoms and pain/irritation at the injection site. Rarely, patients may experience high blood pressure and seizures.

Who should not take EPO?

People who are allergic to EPO and people who have uncontrolled high blood pressure should not take it.



Should I be on EPO if I am pregnant or nursing?

Do not use this medication without talking to your doctor if you are pregnant or if you are breast-feeding .

How do I store EPO?

EPO should be stored in your fridge, between 2°C and 8°C (35-46°F). Do not shake the bottle. Store out of direct sunlight.

Can I travel with my EPO?

Yes. You will need to keep the EPO refrigerated or in a cooler with ice packs. Do not place vials directly on ice and do not allow them to freeze. Do not use dry ice.☀

JHVC FACULTY AND STAFF

Faculty

John Stone, MD, MPH
Director

David Hellmann, MD, MACP
Executive Director

Geetha Duvuru, MD
Assistant Professor

Stuart Levine, MD
Assistant Professor

Philip Seo, MD
Assistant Professor

Physician Assistant

Matthew Marriott, PA-C, MS
Physician Assistant-Certified

Research Staff

Lourdes Pinachos, RN, BSN
Research Program Supervisor

Karen Gauss, 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 Coord./Registrar

Communications

Stacey LaBahn
Communications Coordinator

JHVC IN THE NEWS SPRING/SUMMER 2005

New Faculty and Staff

Duvuru Geetha, M.D.

Dr. Geetha is an Assistant Professor of Medicine in the division of nephrology. A graduate of Madras



Medical College, India, she completed Internal Medicine training in U.K. She did her Internal Medicine Residency at York, PA and Nephrology fellowship at Johns

Hopkins Bayview Medical Center. She has been on Hopkins faculty since 1998. She is a member of Royal College of Physicians (U.K.), American Society of Nephrology, International Society of Nephrology and American Society of Transplantation.



Ms. Karen Gauss, R.N., M.L.A.— Research Coordinator

Karen joined the Johns Hopkins Vasculitis Center in April 2005. Ms. Gauss has more than 15 years experience working at Bayview and extensive experience as a research nurse and coordinator. She received her Bachelor's degree in

Nursing from York College of Pennsylvania and Master's degree in Liberal Arts from the Johns Hopkins University. Jumping feet first into JHVC projects, she'll be coordinating several new studies that start in the later part of the summer. Beyond work, her busy life includes her husband, Roger, and her two wonderful boys, Jacob (8) and William (5).

Weddings

Judy (Harrison) Wise—Our most heart-felt congratulations go out regarding the marriage of Judy (Harrison) and John Wise celebrated on May 14, 2005. Many know Judy from her role as the first Patient Care Coordinator for the Vasculitis Center, and, currently, in her role as the Rheumatology Division Clinic Supervisor. Many glad tidings!



ΕΛΛΗΝΙΚΗ ΡΕΥΜΑΤΟΛΟΓΙΚΗ ΕΤΑΙΡΕΙΑ	
ΔΙΑΛΕΞΗ	Προεδρεία: Δ. Βασιλιάνου - Γ. Φωτακόπουλος
J. Stone:	Conventional approaches to the therapy of systemic vasculitides how bad (and good) are they?
ΔΙΑΛΕΞΗ	Προεδρεία: Α. Σακκάς - Γ. Καραγκιάνος
J. Stone:	Vasculitis: pearls and myths
Διαθέσιμα - Καρτές (Καρτώς SANOFI - AVENTIS)	

It's all Greek to Me!

Dr. John Stone gave three talks at the Panhellenic Society for Rheuma-

JHVC IN THE NEWS SPRING/SUMMER 2005

tology in Athens, Greece (November 2004). He was pleased to renew associations with several Greek colleagues, including the President of the Society, Dr. Dimitrios Boumpas, as well as Drs. Ionnadis Boletis (a nephrologist with a special interest in vasculitis) and Dr. Dimitrios Vassilopoulos (a rheumatologist). Dr. Stone's family traveled with him. (see photo—right)

Dr. Philip Seo received a Patient-Oriented, Career Development Research Award from the National Institute of Arthritis, Musculoskeletal, and Skin Diseases, a branch of the National Institutes of Health (NIH). This 5-year award will support Dr. Seo's efforts in clinical and translational research in vasculitis. Dr. Seo's grant score of 141 placed him easily above the 95th percentile among applicants!

Mrs. Lourdes Sejismundo, RN BSN presented "Biologic Therapies for Vasculitis: Implications for Nursing" at the Infusion Nurses Society annual conference in Orlando, Florida. The presentation covered infusion practices and medications used in current vasculitis research.

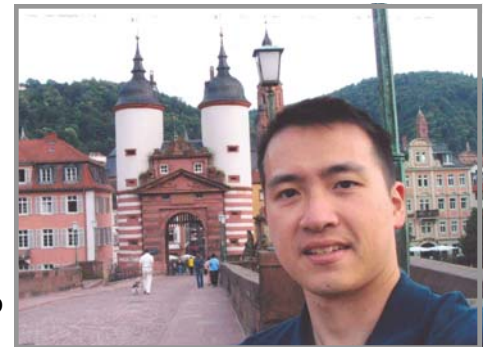
Dr. David Hellmann was named a Master of the American College of Physicians, a signal achievement marking his career-long contributions to the field of Internal Medicine. Dr. Hellmann was inducted as a Master at a ceremony in San Francisco in April, 2005.

Dr. Peter Wung, an Internal Medicine Resident at the Johns Hopkins Bayview Medical Center, gave a talk at the International Vasculitis/ANCA Workshop in Heidelberg, Germany. Dr. Wung's talk described the frequency of occurrence and risk factors for the development of shingles in Wegener's granulomatosis. The results of his research will be published in the American Journal of Medicine this November. At the Heidelberg Meeting, Drs. Wung and Stone were reunited with Oemer Goek (now Dr. Oemer Goek), a German medical student who rotated through the Vasculitis Center in the fall of 2004 and recently graduated from the University of Heidelberg. (see photos—right)

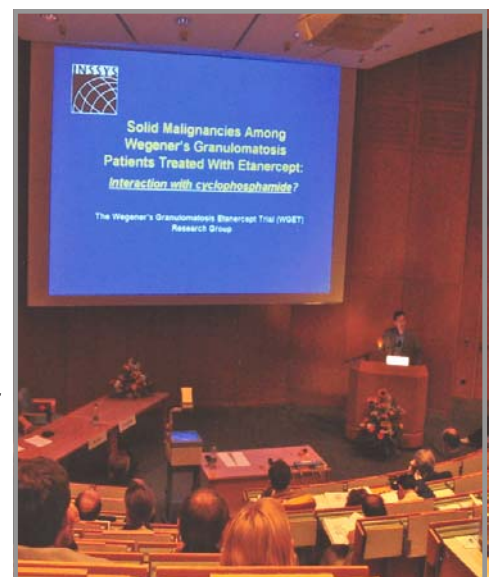
The Johns Hopkins Vasculitis Center was highlighted in the Spring 2005 edition of *Bayview News*, a Hopkins publication circulated to approximately 150,000 people in the Baltimore/Washington area. The article highlights stories initially published in the JHVC newsletter and focuses on raising awareness of vasculitis. To obtain a copy of the article go to <http://www.jhbmc.jhu.edu/OPA/baynews/baynews.html>.



GREECE: Martha, Sarah (9), and William (4), with Dr. Stone at the ancient city of Kamiros.



GERMANY: Dr. Peter Wung at the scenic gates of Heidelberg. Photo taken while attending The International Vasculitis/ANCA Workshop.



GERMANY: Dr. Stone presenting WGET findings at the International Vasculitis/ANCA Workshop, Heidelberg.



CLINIC CORNER: REGISTRATION AND CHECK-OUT

Everyone needs a bit of elbow room! In May, the Division of Rheumatology upgraded the registration desk to include two patient check-out bays. The workstations are designed to provide patients a more comfortable arrangement to close out their visit and set their next appointment. It also provides more privacy than is possible in the JHVC Patient Care Coordinator's office. The workstations, located in the hallway that lead to

and from the exam rooms, are an extension of the registration desk where Ms. Estelle manages sign in and registers patients.

When you come in for visits, register with Ms. Estelle, as usual, but when your visit is finished look for Cynthia Bethea or Sidone Lawrence, the Vasculitis Center Patient Care Coordinators, in either the workstation bay or behind the registration desk to conclude your appointment and make arrangements for your next visit. ☀



Cynthia kindly let us take a photo while she assists a patient caller.

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

We're on the web @

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