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David Hellmann, MD
Executive Director

Michael Regan, MD, MRCP
Instructor in Medicine

Clinical Coordinators

Judy Harrison
Senior Clinic Coordinator

Chasity Harrison
Clinic Coordinator

Research Staff

Misty Uhlfelder
Senior Research Coordinator

Amanda Masterson
Research Coordinator

Ahmed Aldilaimi, MD
Clinical Trials Coordinator

Dear Patients and Friends,

The Faculty and Staff of The Johns Hopkins Vasculitis Center are pleased to present the first quarterly Vasculitis Center Newsletter. This is one way for us to keep in touch with you about the work going on at the Center. We appreciate the support you have given the Center in the past, and want to let you know how your contributions are aiding our research, improving patient care, and helping in the fight against these diseases.

Dr. Regan joins the Faculty

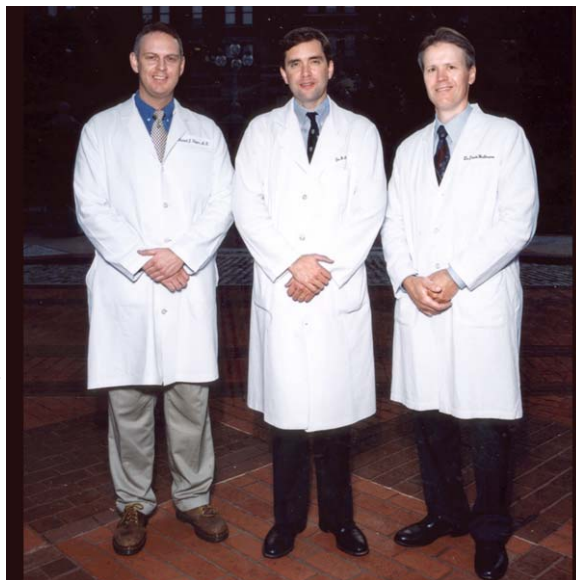
On July 1st, the Center was strengthened by the addition of a new faculty member. **Michael J. Regan, M.D.**, a member of the Royal College of Physicians, joined the Center Faculty as an Instructor in Medicine. A native of Ireland, Dr. Regan attended medical school at the National University of Ireland, Galway. He then performed

his residency at the Newton-Wellesley Hospital, a Tufts-affiliated hospital in the Boston area. He recently completed a 3-year Rheumatology Fellowship at Johns Hopkins. Over the last two years, Dr. Regan has devoted the majority of his clinical time and research efforts to people with vasculitis.

The addition of Dr. Regan expands the capabilities of the Center substantially. His arrival will permit us to increase the number of vasculitis patients evaluated at Johns Hopkins. Dr. Regan will also continue his clinical research, including the development of a new clinical trial for patients with severe vasculitis, investigation of new methods for assessing disease activity, and research into infectious causes of vasculitis. Finally, Dr. Regan will augment the education mission of the Center, working to keep patients and physicians abreast of developments in these diseases.

Amanda Masterson: New Research Coordinator

This summer, we also welcomed a new member to the Research Staff of the Center. **Mandy Masterson, B.S.**, recently moved to Maryland from Colorado, where she attended Colorado State University and majored in Health and Exercise Science. Mandy will enhance the Center's database capabilities, coordinate efforts to improve the webpage (<http://vasculitis.med.jhu.edu>), oversee the organization of grant proposals, and spearhead new research projects. In her short time at the Center, she has already coordinated 3 grant submissions and is working on her fourth!



The Vasculitis Center physicians in front of the Johns Hopkins Hospital. From left to right: Drs. Michael Regan, John Stone, and David Hellmann.

Updates on several current research projects

The Wegener's Granulomatosis Etanercept Trial (WGET)

WGET is a multi-center clinical trial developed and coordinated at Johns Hopkins. The trial is the first clinical trial in vasculitis funded by the National Institutes of Health (NIH). **Dr. John Stone**, Director of the Center, is the Principal Investigator for the trial. Over the first year of enrollment, the 8 centers in the U.S. involved in

the trial enrolled nearly 50% more patients than expected (see Table, right). This swift enrollment should ensure that the results of this trial are available more quickly.

WGET

- First U.S. multi-center trial in WG
- First NIH-funded trial in vasculitis
- Enrollment ahead of schedule

The aim of WGET is to evaluate the effectiveness and safety of etanercept (Enbrel™; Immunex Corporation; Seattle) in treating WG. Etanercept works by blocking a specific protein that is believed to play a central role in WG. The hope of the WGET Research Group is that etanercept will provide a safer and more effective means of treating WG. Enrollment in WGET will continue until September, 2002.



Dr. Ahmed Aldilaimi is the Clinical Trials Coordinator of the Johns Hopkins WGET site.

The Wegener's Granulomatosis Etanercept Trial: Expected Versus Actual Enrollment, Year One

Clinical Site	Patients Screened for Trial	Expected	Actual	Percent above expected enrollment
Cleveland Clinic Foundation	143	9	23	155%
Johns Hopkins University	122	9	19	111%
The Mayo Clinic	184	9	18	100%
Beth Israel Medical Center	43	9	14	56%
Boston University	51	9	12	33%
University of CA, San Francisco	29	9	11	22%
Duke University	59	9	6	NA
University of Michigan	8	9	3	NA
Totals	639	72	106	47%

Table. 639 patients were screened for WGET in Year 1 (only patients with active disease are eligible for enrollment). Each clinic was expected to enroll a minimum of 9 patients during this period. As the Table shows, 6 of the 8 clinics exceeded their enrollment aims dramatically. Enrollment in Year 1 was 47% more brisk than anticipated.

WGET is funded by NIAMS (the National Institute of Arthritis, Musculoskeletal, and Skin Diseases, an NIH institute), and by the FDA (Food and Drug Administration, Office of Orphan Products Development).

Once patients have been treated at the Center, they often ask what they can do to help improve treatment for future patients. Johns Hopkins is an active research center. Research is crucial to the discovery of causes, treatments, and cures for vasculitis. Much of this research is made possible by private support. If you would like to support vasculitis research for the benefit of others, please send your tax deductible contribution, payable to The Johns Hopkins Vasculitis Center (1830 E. Monument Street, Suite 7500, Baltimore, MD 21205). If you have questions about philanthropic giving, please call Tom Anderson at the Department of Medicine, (410) 614-6700.

Infectious Causes of Giant Cell Arteritis

Patients and physicians have long wondered if giant cell arteritis (GCA), also known as “temporal” arteritis (see Figure, right), is caused by some type of infection. Bacteria have been suggested as causes of other forms of blood vessel disease. In particular, a bacterium known as *Chlamydia pneumoniae* is suspected of playing a role in arteriosclerosis, (“hardening of the arteries”), the most common cause of heart disease in the world.

Because of similarities between GCA and arteriosclerosis, some doctors have suggested treating GCA with antibiotics, even though no association between GCA and *C. pneumoniae* has ever been proven. A study recently completed at the Center indicates that calls for the use of antibiotics to treat GCA are premature. With colleagues in the Division of Infectious Diseases at Johns Hopkins (**Drs. Charlotte Gaydos and Thomas Quinn**), the research team examined temporal artery biopsies

This study was funded jointly by the **Peggy Meyerhoff Pearlstone Foundation** and the National Heart, Lung, and Blood Institute.

specimens from 90 patients with GCA and 90 controls.

The total of 180 patients in this study is approximately ten times more than any previous investigation of this question. The biopsies, collected in the context of routine care, were stored in The Johns Hopkins Wilmer Eye Institute between 1968 and 2000. The investigators used a sensitive technique known as *polymerase chain reaction*, which detects, even minute quantities of bacterial DNA. The results will be published this winter in Arthritis and Rheumatism: no association between *C. pneumoniae* and GCA.

Investigators at the Center continue to evaluate possible infectious causes of GCA, and are currently exploring the role of viruses in triggering this disease.



A swollen, inflamed artery over the temple in a patient with giant cell arteritis.

Patients' Quality of Life in Giant Cell Arteritis

Currently, it is estimated that 110,000 people in the U.S. have GCA. For decades since its first clinical description in the 1890s, patients and physicians have recognized the devastating clinical consequences of this disease. GCA, which typically afflicts individuals older than 50, includes symptoms of severe headaches, muscle and joint pain, fever, weight loss, and inflammation in the aorta and other large arteries. The greatest concern, however, is the risk of sudden blindness.

For the past two years, Center investigators and colleagues at Johns Hopkins have coordinated an international effort to understand the effects of this disease in another way: *its impact on*

patients' quality of life. With **Haya Rubin, MD, PhD** (right), and **Mollie Jencks, MHSc**, experts on the analysis of quality of life issues for patients, the Center has organized researchers from the U.S., Scotland, France, and Spain to develop an effective means of evaluating the quality of life for patients with GCA. To date, 150 patients and researchers from 10 international medical centers have participated in this effort. The results of this collaboration will be presented at the American College of Rheumatology meeting in San Francisco (November, 2001). The instrument will also be incorporated into upcoming clinical trials in GCA.



Dr. Haya Rubin, an expert in studies evaluating patients' quality of life, has collaborated with the Center investigators on a recent study.

The efforts of this international group of investigators to develop a quality of life instrument in GCA has been supported by a generous grant from the **Sacharuna Foundation.**

Clinic Corner



Senior Clinic Coordinator Judy Harrison
with V.Z., a Vasculitis Center patient.

In serving people with vasculitis, the Center boasts the talents of two remarkable Coordinators of patient care: Judy and Chasity Harrison. After appointments at the Center, most patients say: “O.K., now I want to meet Judy and Chas.” Here are 5 tips from Judy and Chas about ways to make your appointment run smoothly:

1. Bring all necessary referrals with you.
2. Arrive 30 minutes early.
3. Bring all of your medications to clinic, not just a list of them.
4. If your laboratory work is not done at Hopkins, you need to make sure that the results are faxed to us at (410) 614-7148.
5. If you cancel an appointment through our automated confirmation line, please also inform Judy or Chas at (410) 955-1735 as soon as possible.

Topics for Upcoming Newsletters

- Proteomics: a cutting edge approach to evaluating vasculitis activity
- “Immunoablative” therapy for patients with refractory vasculitis

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

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