

8th International Vasculitis Symposium

The Vasculitis Journey: Knowledge • Community • Hope

June 6-8, 2008

Mayo Clinic, Rochester, Minnesota

Program Schedule - Revised 5.22.08

FRIDAY, JUNE 6, 2008

10:00 a.m.

Registration Desk Opens

Location: Mezzanine Level - The Kahler Grand Hotel

1:00 p.m. – 4:30 p.m. (with break from 2:30 – 2:45 p.m.)

Vasculitis: What to know, what to expect at different stages

Kick off your symposium weekend as this expert medical panel provides general overviews on the most common areas of concern for vasculitis patients. The session will provide ample time for Q&A from the audience.

Panel:

Ulrich Specks, M.D., Session Moderator, Pulmonary and Critical Care Medicine, Mayo Clinic

Jan L. Kasperbauer, M.D., Otorhinolaryngology, Mayo Clinic

Fernando C. Fervenza, M.D., Nephrology and Hypertension, Mayo Clinic

Eric L. Matteson, M.D., Rheumatology, Mayo Clinic

James A. Garrity, M.D., Ophthalmology, Mayo Clinic

Phillips Hall, Siebens Medical Education Building

1:00 p.m. - 4:30 p.m. (with break from 2:30 – 2:45 p.m.)

From Childhood to Adulthood - Vasculitis and our Pediatric Patients and their Parents

Join parents and young patients as our pediatric vasculitis experts discuss the management and treatment of vasculitis for our younger patients. Attendees will be able to ask questions, meet other parents/patients and share experiences, concerns and what works for them.

Panel:

Phillip Hashkes, M.D., Session Moderator, Rheumatic and Immunologic Disease, Cleveland Clinic

Mark E. Wylam, M.D. Pediatrics, Pulmonary and Critical Care Medicine, Mayo Clinic

J. Michael Bostwick, M.D., Psychiatry and Psychology, Mayo Clinic

Nygaard Lecture Hall (Room #405), Siebens Medical Education Building

FRIDAY, JUNE 6, 2008 continued

3:00 p.m. - 4:30 p.m. **Patients in Transition: From Young Adulthood to Adulthood**
(Only patients will be allowed in this session.)

So, you're in your late teens/early 20s and you've got a chronic illness most people have never heard of - now what? Join other patients and Dr. Bostwick, a psychiatrist, and Terra Zosel, a patient, for an open and honest discussion on the challenges of making the transition to adulthood. Learn the ins and outs of communicating with your doctor (when your parents aren't around anymore) and share your experiences/challenges living with vasculitis.

Panel:

J. Michael Bostwick, M.D., Psychiatry and Psychology, Mayo Clinic

Terra Zosel, patient, Minneapolis, Minnesota

Grumman Lecture Hall (Room #406), Siebens Medical Education Building

5:00 p.m. **Inaugural Symposium Fun Walk**

Join us for the first-ever walk held during a symposium as we raise awareness of vasculitis and the Vasculitis Foundation. Walk with the group or cheer people on. The goal is to attract the attention of the local media and citizens of Rochester.

Mayo Campus - meet in the grassy area between the Kahler Grand Hotel and Marriott

Friday Evening Dinner: **Dinner on your own**

8:00 p.m. – 9:30 p.m. **Dessert Welcome Reception**

Welcome:

Phyllis Lasky, President, VF Board of Directors

Ulrich Specks, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

SATURDAY, JUNE 7, 2008

7:00 a.m. – 7:45 a.m. **Continental Breakfast / VF Annual Membership Meeting starts at 7:15**
The Kahler Grand Hotel Heritage Ballroom (subway level)

MORNING SESSION: Phillips Hall, Siebens Medical Education Building

8:00 a.m. – 8:15 a.m. **Welcome:** Phyllis Lasky, President, VF Board of Directors
Ulrich Specks, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

8:15 a.m. – 8:55 a.m. ***General Talk #1: Advances in Basic Science Research and What They Mean for Vasculitis Patients*** –Ronald Falk, M.D., Division of Nephrology & Hypertension, University of North Carolina

8:55 a.m. – 9:35 a.m. ***General Talk #2: State of Clinical Research for Vasculitis Patients***
Carol Langford, M.D., Cleveland Clinic Center for Vasculitis Care and Research

9:35 a.m. – 10:15 a.m. ***General Talk #3: Why Vasculitis Patients Should Participate in Clinical Studies*** - Peter Merkel, M.D., Vasculitis Center, Boston University

10:15 a.m. – 10:45 a.m. **MORNING BREAK**

SATURDAY, JUNE 7, 2008 continued

There will be four Breakout Session timeslots on Saturday and one on Sunday. The sessions provide the opportunity to explore specific topics in depth. Please review the entire schedule as some topics will be repeated, while others will only be offered once. Medical experts will answer questions from the audience. Please choose ONE topic to attend each session.

* indicates session moderator

10:45 a.m. – 11:45 p.m. **BREAKOUT SESSION #1 (choose one to attend)**

Ear/Nose/Throat Clinical Presentations

Learn about ENT symptoms, the most current therapies, and management of vasculitis.

Panel:

Jan L. Kasperbauer, M.D., Otorhinolaryngology, Mayo Clinic

*Robert Lebovics, M.D., Otolaryngology/Head and Neck Surgical Group,, St. Lukes-Roosevelt Hospital Center

Robert Lorenz, M.D., Head & Neck Institute, Cleveland Clinic

Location TBA

Eyes

Learn about ocular symptoms, the most current therapies, and management of vasculitis.

Elizabeth A. Bradley, M.D., Ophthalmology, Mayo Clinic

Location TBA

Nutrition

Back away from those cheeseburgers! Learn how healthy eating can help you while on therapy and beyond.

Jacalyn A. See, Registered Clinical Dietitian, Mayo Clinic

Location TBA

Rheumatology I - Remission: Getting There, Staying There

The elusive “R” word: Strategies for working with your medical team to achieve and sustain remission.

Panel:

*Nabih Abdou, M.D., The Center for Rheumatic Diseases & Allergy – Immunology

Gary S. Hoffman, M.D., Cleveland Clinic Center for Vasculitis Care and Research

Eric L. Matteson, M.D, Rheumatology, Mayo Clinic

Location TBA

11:45 p.m. – 1:00 p.m.

BOXED LUNCH

Individual disease groups will meet during this time. Pediatric patients and families are invited to attend a session with pediatric physicians.

SATURDAY, JUNE 7, 2008 continued

1:00 p.m. – 2:00 p.m. BREAKOUT SESSION #2 (choose one session to attend)

Kidneys: Strategies for Maintaining Kidney Function

Learn how to protect and preserve your kidney function.

Panel:

*Ronald Falk, M.D., Division of Nephrology & Hypertension, University of North Carolina

Fernando C. Fervenza, M.D., Nephrology and Hypertension, Mayo Clinic

Location TBA

Lungs

Learn about thoracic symptoms, the most current therapies, and management of vasculitis.

Karina Keogh, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

*Ulrich Specks, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

Location TBA

Pediatrics

Our younger patients are not the same as our adult patients. This session will address topics/concerns discussed during earlier sessions and how/if they apply to pediatric patients.

Panel:

*Mark E. Wylam, M.D. Pediatrics, Pulmonary and Critical Care Medicine, Mayo Clinic

Ann Reed, M.D., Pediatrics, Rheumatology, Mayo Clinic

Location TBA

Rheumatology II

So, you've tried Cytoxan, CellCept, Methotrexate, Imuran, steroids and the list goes on... What's next? Ask the experts about juggling ongoing symptoms when remission is elusive.

Panel:

Nabih Abdou, M.D., The Center for Rheumatic Diseases & Allergy – Immunology

*Philip Seo, M.D., The Johns Hopkins Vasculitis Center

Location TBA

Subglottic Stenosis and Vasculitis Patients

Subglottic stenosis is a challenging vasculitis condition. Learn from experts about best practices used to treat it.

Panel:

Jan L. Kasperbauer, M.D., Otorhinolaryngology, Mayo Clinic

*Robert Lorenz, M.D., Otolaryngology, Head and Neck Institute, Cleveland Clinic

Location TBA

AFTERNOON GENERAL TALKS: Phillips Hall, Sieben's Medical Education Building

2:15 p.m. – 2:45 p.m.

General Talk #5: *Clinical Lab Monitoring of the Vasculitis Patient*

Ulrich Specks, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

2:45 p.m. – 3:15 p.m.

General Talk #6: *The Heart of the Vasculitis Patient*

Garvan C. Kane, M.D., Cardiovascular Diseases, Mayo Clinic

SATURDAY, JUNE 7, 2008 continued

3:30 p.m. – 4:30 p.m. **BREAKOUT SESSION #3 (choose one to attend)**

Ear/Nose/Throat Clinical Presentations

Learn about ENT symptoms, the most current therapies, and management of vasculitis.

Panel:

Jan L. Kasperbauer, M.D., Otorhinolaryngology, Mayo Clinic

*Robert Lebovics, M.D., Otolaryngology/Head and Neck Surgical Group, St. Lukes-Roosevelt Hospital Center

Location TBA

Kidneys: Strategies for Maintaining Kidney Function

Discuss kidney function and what lab values are and tell about your kidneys.

Panel: *Ronald Falk, M.D., University of North Carolina

Fernando C. Fervenza, M.D., Nephrology and Hypertension, Mayo Clinic

Location TBA

Lungs

Learn about thoracic symptoms, the most current therapies and management of vasculitis.

Karina Keogh, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

*Ulrich Specks, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

Location TBA

Mayo Nurses Patient Education Program: Marriott Ballroom

The nurses at the Mayo Clinic have a long tradition of educating patients about their diseases and have organized a hands-on educational session for attendees to learn more about the following topics:

Dermatology: Sheila J. Larson, L.P.N., and Ronda L. Kaiser, R.N.

Discuss general sun exposure safety points. Review some of the medications used for treating vasculitis that have sun exposure safety warnings. Review care of a skin biopsy.

Ear/Nose/Throat: Lucinda L. Hinkley, R.N.

The ins and outs of nasal irrigation including strategies, formulas and techniques.

Let's Talk "Healthy Living": Susan D. Fisher, R.N.

As a patient, sometimes making those "healthy" choices is not as easy as it seems. Let's talk about some ways to create healthy living for you.

Ophthalmology: Susan A. McIntire, R.N.

View and discuss a poster with common questions and answers concerning eye care. Review of red eye (subconjunctival hemorrhage, conjunctivitis, episcleritis, and scleritis). Provide information on current eye drops and the proper administration of the eye drops.

Pulmonary: Sharon D. Bendel, R.N., and Mary Lou Clawson, R.N., Susan D. Fisher, R.N.

Inhaler technique review including explanation of the actions of the various medications. Proper administration techniques for each delivery system will be explained and demonstrated. Peak Flow Meter's role of monitoring tracheal stenosis will be discussed. The appropriate technique necessary to obtain accurate measurement will be shown.

Rheumatology: Lisa Von Wald, R.N. *What are the medications you use for your disease and what tests and follow-up are required for them.*

SATURDAY, JUNE 7, 2008 continued

Pharmacist

Just say no to Echinacea. Learn about the drugs used to treat your vasculitis, supplements- and resources for determining what may help and what will harm.

Chris Arendt, Pharm.D., St. Mary's Hospital, Mayo Clinic

Gary S. Hoffman, M.D., Cleveland Clinic Center for Vasculitis Care and Research.

Phillips Hall, Siebens Medical Education Building

Rheumatology III: Quality of Life

Facing a chronic illness challenges one's quality of life. Learn how to increase and maintain your quality of life while living with vasculitis.

Panel:

*Carol Langford, M.D., Cleveland Clinic Center for Vasculitis Care & Research

Philip Seo, M.D., The Johns Hopkins Vasculitis Center

Nabih Abdou, M.D., The Center for Rheumatic Diseases & Allergy – Immunology

Location: TBA

4:45 p.m. – 5:45 p.m. BREAKOUT SESSION #4 (choose one session to attend)

Caregivers

Caregivers are the key to every vasculitis patient. Share effective caregiving strategies and learn how to sustain yourself and the patient's support team.

Panel:

Julie Garten-Good, VF Education & Awareness Council; Jeanne Cappa, VF Education & Awareness Council; Bob Sahs, VF Board of Directors

*Nabih Abdou, M.D., The Center for Rheumatic Diseases & Allergy – Immunology

Location: TBA

Caring for Yourself Through Mind, Body and Spirit

Experience the benefits of chair yoga, relaxation, massage and humor therapy to refresh your mind, body, and spirit. These stress management and coping techniques can work wonders for the caregiver and the patient. Make time for yourself to relax, refresh and reward.

Brooke L. Werneburg, Mayo Clinic- Dan Abraham Healthy Living Center

Location TBA

Infertility - Planning for your future Family

Some of the drugs used to treat vasculitis can result in infertility and sterility. Learn about the risks and what questions to ask of your physician about therapies. Discuss the types of medical experts who can help you with this critical issue.

Tobias Peikert, M.D., Mayo Clinic, and Charles C. Coddington, M.D., Professor of Obstetrics-Gynecology, Mayo Clinic

Location TBA

Subglottic Stenosis

Subglottic stenosis is a challenging vasculitis condition. Learn from experts about best practices used to treat it.

Jan L. Kasperbauer, M.D., Otorhinolaryngology, Mayo Clinic

Location: TBA

SATURDAY, JUNE 7, 2008 continued

7:00 p.m. Celebration Banquet

Special Guest Speaker: Dr. Nick Mezacapa has inspired audiences across the country with his unique and unforgettable presentations. Nick's style weaves captivating personal life experiences with the refreshing and inspiring message he has to share.

The Kahler Grand Hotel Heritage Ballroom (subway level)

SUNDAY, June 8, 2008

7:00 a.m. – 8:15 a.m. **Continental Breakfast** (informal, no program)
The Kahler Grand Hotel Heritage Ballroom (subway level)

MORNING SESSION: Phillips Hall, Siebens Medical Education Building

Welcome and Introductions: Eric Matteson, M.D., Rheumatology, Mayo Clinic

8:30 a.m. – 9:00 a.m. **General Talk #1: *Developing Drugs and Medical Devices: Making Treatments Safer for Vasculitis Patients*** - Gary S. Hoffman, M.D., Cleveland Clinic, Center for Vasculitis Care and Research

9:00 a.m. – 9:30 a.m. **General Talk #2: *The Skin of the Vasculitis Patient***
Lawrence E. Gibson, M.D., Anatomic Pathology, Dermatology, Mayo Clinic

9:30 a.m. – 10:00 a.m. **MORNING BREAK**

10:00 a.m. – 11:00 a.m. **BREAKOUT SESSION #1**

Better Care through Better Communication

How to get better care through better communications. Giving patients skills and permission to develop effective communications w/care team.

Jeffrey T. Rabatin, M.D., Pulmonary and Critical Care, Mayo Clinic

Phillips Hall, Siebens Medical Education Building

Hearing/Ear

How does vasculitis affect the ears and what can be done about hearing loss and other ear symptoms?

Brian A. Neff, M.D., Otorhinolaryngology, Mayo Clinic

Location TBA

Laboratory Testing in Vasculitis Patients: What, When and Why

Learn what the different laboratory test results mean, which ones you should have and at what frequency.

*Ulrich Specks, M.D., Pulmonary and Critical Care Medicine, Mayo Clinic

Peter Merkel, M.D., Vasculitis Center, Boston University

Peripheral Neuropathy - When the nerves go haywire

When the peripheral nerves fail to function properly, this results in pain, loss of sensation, or inability to control muscles. Learn strategies and treatment possibilities for dealing with peripheral neuropathy.

Paola Sandroni, M.D., Neurology, Mayo Clinic

Location TBA

SUNDAY, June 8, 2008 continued

FINAL SESSION: Phillips Hall, Siebens Medical Education Building

11:15 a.m. – 11:45 a.m. **General Talk #3: *Complementary Medicine and the Vasculitis Patients***
Brent A. Bauer, M.D., General Internal Medicine, Mayo Clinic

11:45 a.m. – 12:15 p.m. **General Talk #4: **Individualized Medicine and What it Means to Vasculitis Patients in the Future****
Eric L. Matteson, M.D, Rheumatology, Mayo Clinic

12:15 p.m. **Wrap-up and Farewell:** Cassie Keane, 2008-2009 President, VF Board of Directors