



Stanford University School of Medicine

and the

VHL Family Alliance



Present

Health Management in von Hippel-Lindau

**Eighth Annual Conference on
von Hippel-Lindau Disease**

A Continuing Medical Education Course for
Physicians and Health Care Professionals

22-24 June, 2001

Fairchild Auditorium, Stanford University

Palo Alto, California

Chaired by:

John R. Adler, Jr., M.D., Dept of Neurosurgery

Joyce Wilcox Graff, VHL Family Alliance

This activity has been planned and implemented in accordance with the Essentials and Standards of the Accreditation Council for Continuing Medical Education through the joint sponsorship of Stanford University School of Medicine and the VHL Family Alliance. The Stanford University School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.



Non-Managed Symposia Course

Category 1 CME Credit

OPGME – attention Kari Costa

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SPEAKER AFFILIATIONS SUMMARY

**Department of Neurosurgery
Health Management in von Hippel-Lindau
June 22-24, 2001
Fairchild Auditorium
(Course # VHLFA)**

In accordance with the standards of the Accreditation Council for Continuing Medical Education, all speakers at this program have been asked to disclose any real or apparent conflicts of interest which may have a direct bearing on the subject matter they will be presenting at this program.

The following have indicated a financial interest or affiliation which may affect their presentation(s):

John R. Adler, Jr., M.D.

CEO of Accuray, manufacturer of the Cyberknife. The Cyberknife is one type of radiosurgical instrument that can be used to treat hemangioblastomas and other tumors.

The following have indicated no financial interest or affiliation which may affect their presentation(s)

Ronald Bachman, M.D.

Dawn Cerf

Hetty DeVroom, R.N.

Myriam Gorospe, Ph.D.

Joyce Wilcox Graff

Elson Haas, M.D.

Peter Jackson, Ph.D.

Peggy J. Marshall

Jay Platt

Thomas D. Rodenberg, Esq.

Maria Shipton

Robert Williams, M.S., M.D.

This information is disclosed in compliance with the Accreditation Council for Continuing Medical Education Standards for Commercial Support of Continuing Medical Education.

Health Management in von Hippel-Lindau

Friday June 22, 2001, 1:00 - 8:00 p.m.

- 12:00 - 1:00** **Registration**
- 1:00 - 1:30** **Welcome, The VHLFA Story, Introduction of Board Members, Chapter Chairpersons, and Conference Hosts**
Dawn Cerf, California Chapter Chair, San Luis Obispo, California
Peggy J. Marshall, Chair VHL Family Alliance, Corinth, Mississippi
- 1:30 - 2:15** **Clinical Evaluation and Health Management in VHL**
Hetty L. DeVroom, R.N., BSN, CNRN, National Institute of Neurological Disorders and Stroke. Report from the VHL Clinic, Cancer Diagnostic Branch, National Cancer Institute, Rockville, Maryland
- 2:15 - 2:30** **VHL Clinical Care Centers**
Joyce Graff, Editor; Chair, Clinical Care Centers, VHL Family Alliance
- 2:30 - 3:00** **Break**
- 3:00 - 3:45** **Genetic Testing for von Hippel-Lindau**
Ronald P. Bachman, M.D., Chief, Department of Genetics, Kaiser-Permanente Oakland Hospital
- 3:45 - 4:30** **Ophthalmological Issues in VHL**
Wayne E. Fung, M.D., Clinical Professor of Ophthalmology, California Pacific Medical Center, San Francisco.
- 4:30 - 5:15** **Stereotactic Radiation -- what, when, and why**
John R. Adler, Jr., M.D., Professor of Neurosurgery and Radio Oncology, Stanford University
- 5:15 - 6:30** **Relocate to the hotel**
- 6:30 - 8:00** **Dinner Meeting, at the Sheraton Palo Alto**
- Getting Acquainted, Untying the Knot**

Saturday, June 23, 2001 7:30 a.m. - 5:30 p.m.

- 7:30 - 8:30** **Breakfast Provided**
- 8:30 - 9:15** **Integrated Medicine and Chronic Illness**
Elson M. Haas, M.D., Medical Director, Integrated Medicine, Preventive Medical Center of Marin, San Rafael, California
- 9:15 - 10:00** **VHLFA Research Grant Awards, 2001-2002**
Myriam Gorospe, Ph.D., Director of Research, VHL Family Alliance, Baltimore, Maryland
- 10:00 - 10:15** **Break**

- 10:15 - 11:00** **Advances in Diagnostic Imaging**
Randall Hawkins, M.D., Ph.D., Radiology
University of California, San Francisco
- 11:00 - 11:45** **Pregnancy and VHL**
Dr. Yasser El-Sayed, M.D., Assistant Professor, Division of Maternal-Fetal
Medicine, Stanford University Medical Center
- 12:00 - 12:45** **Lunch Provided**
- 12:45 - 1:15** **VHL Family Alliance Annual Meeting, Nomination and Election of
Board Members**
- 1:15 - 1:30** **Break, return to auditorium**
- 1:30 - 2:00** **Advances in Treatment of Brain and Spinal Tumors**
Mitchel S. Berger, M.D., Chief, Department of Neurosurgery
University of California, San Francisco
- 2:00 - 2:45** **Finding Elusive Pheochromocytomas**
Graeme Eisenhofer, Ph.D., Director, Clinical Neurochemistry Laboratory,
Clinical Neurocardiology Section, National Institute of Neurological
Disorders and Stroke, National Institutes of Health, Bethesda, Maryland
- 2:45 - 3:15** **Break**
- 3:15 - 4:00** **Kidney Issues in VHL**
Fabián Fonseca Guzmán, M.D., Ph.D., Urologic Surgery, University of
Costa Rica, Quindío, Costa Rica. Translation by Myriam Gorospe, Ph.D.
- 4:15 - 5:00** **Kidney Transplantation for people with VHL**
Oscar Salvatierra, Jr., M.D., Professor of Surgery and Pediatrics and
Director of Pediatric Renal Transplantation, Stanford University Medical
Center.
- 5:00** **Dinner on your own**

Sunday June 24, 2001 7:30 - 1:15 p.m.

- 7:30 - 8:30** **Breakfast - Provided**
- 8:30 - 9:15** **Sunday Meditation - Coping**
Dawn Cerf, Tai Chi demonstration and instruction in simple Tai Chi
breathing exercises and movements (any clothing acceptable)
- 9:15 - 10:15** **Insurance and Legal Issues**
Thomas D. Rodenberg, Esq., Jeter, Rains, & Byrn, Blue Springs,
Missouri
- 10:15 - 10:45** **Break**

10:45 - 11:30

Utilization Management and Multi-system disorders like VHL

Robert Williams, M.S., M.D.

Medical Director, Gould Medical Foundation, Tracy, California

11:45 - 12:30

Biomedical Research on VHL

Peter Jackson, Ph.D., Assistant Professor of Pathology, Microbiology and Immunology, Stanford University Medical Center

12:45 - 1:15

Meeting Summary

Patricia Rasmussen, Peggy Marshall

POSTER PRESENTATION

Urologic Aspects of VHL

Fabián Fonseca Guzmán, M.D., Ph.D., Costa Rica

FACULTY

John R. Adler, M.D., Professor of Neurosurgery and Radio Oncology, Stanford University. Dr. Adler received his MD from Harvard in 1980. He interned at Brigham Hospital and completed a neurosurgery residency at Massachusetts General. From 1986 to 1987 he served as chief resident in neurosurgery at Children's Hospital-Brigham and Women's. He joined Stanford in 1987 as an assistant professor and became an associate professor in 1993. Dr. Adler has played a critical role in Stanford's radiosurgery program. He has done pioneering work in the development of minimally invasive image-guided surgical tools and, in particular, in the use of stereotactic neurosurgery to treat meningioma. His work involves a strong collaborative effort among faculty in different departments and divisions, including neurosurgery, radiation oncology, computer science and medical informatics.

Ronald Bachman, M.D., Chief, Department of Genetics, Kaiser-Permanente Oakland Hospital. Dr. Bachman has been heading genetic services in Oakland since 1968. Over the past ten years the department has enlarged to 75 people full-time in Genetics. Prior to that time he worked both in General Pediatrics and Genetics. He is working with Kaiser to prepare for the sharp increase expected in requests for genetic services over the next decade among Kaiser's 3.1 million health plan members in Northern California.

Mitchell Berger, M.D., Chief, Department of Neurosurgery University of California, San Francisco (UCSF). After graduating from Harvard University, Dr. Berger complete his medical degree at the University of Miami, with a residency in neurosurgery at UCSF, and a fellowship in Pediatric Neurosurgery at the Hospital for Sick Children, Toronto, Canada. He worked for 11 years at the University of Washington in Seattle, and has been with UCSF since 1997, where he is also Director of the Brain Tumor Research Center. He is the author of numerous professional articles, including several on genetic and metabolic approaches to brain tumor therapy.

Dawn Cerf

Dawn Cerf is the California Chapter Chair of the VHLFA, a writer, the mother of two teenagers, and an inactive C.P.A. She has studied Tai Chi Chuan for seven years, primarily Yang style and recently Chen style, and teaches Tai Chi. For three years, she has also studied Baguazhang,

another Chinese martial art. Dawn has won a few medals for Tai Chi competitions in the U.S. and China.

Hetty L. DeVroom, R.N., BSN, CNRN. Clinical Research Nurse in the Surgical Unit of the National Institute of Neurological Disorders and Stroke, National Institutes of Health, Bethesda, Maryland. Ms. DeVroom has been a key contributor to the VHL Clinical Research Program at the NIH for more than ten years. The program is coordinated by Dr. Gladys Glenn under the Urologic Oncology service at the National Cancer Institute.

Graeme Eisenhofer, Ph.D., Director, Clinical Neurochemistry Laboratory, Clinical Neurocardiology Section, National Institute of Neurological Disorders and Stroke, National Institutes of Health, Bethesda, Maryland. Dr. Eisenhofer graduated with honors from Victoria University of Wellington, New Zealand, and completed his Ph.D. in Human Physiology at the Wellington Clinical School of Medicine, University of Otago, Wellington, New Zealand. After a fellowship at the U.S. National Institutes of Health, he spent three years as Senior Research Officer in the Autonomic Function Unit of the Baker Medical Research Institute, Melbourne, Australia. He has been at the U.S. National Institutes of Health since 1991, where he directs the Clinical Neurochemistry Laboratory. He has over 170 scientific publications including numerous articles in leading medical journals about pheochromocytoma. This work includes introduction of measurements of plasma metanephrines for biochemical diagnosis of pheochromocytoma. He has been praised for his work with patients by the Pheochromocytoma Support Group and the VHL Family Alliance.

Yasser El-Sayed, M.D., Division of Maternal-Fetal Medicine, Stanford University Medical Center. Dr. El-Sayed specializes the management of high-risk pregnancy, including pre-term labor, tocolytic therapy, and antiphospholipid syndrome. He is a member of the North American Society for the Study of Hypertension in Pregnancy.

Wayne E. Fung, M.D., Ophthalmologist, Clinical Professor of Ophthalmology, California Pacific Medical Center, San Francisco. After completing undergraduate training at the University of California Berkeley, Dr. Fung graduated from USC Medical School. He interned at Santa Clara County Medical Center in San Jose, where he did a residency in general surgery. After two years as a Flight Surgeon in the US Air Force, he completed a three-year residency in ophthalmology at Pacific Presbyterian Medical Center in San Francisco. He then completed a fellowship in retinal detachment surgery at Washington University in St. Louis and a year at the Bascom Palmer Eye Institute in Miami, Florida. He has been a practicing retinal specialist for 33 years. Dr. Fung has published extensively on the treatment of macular degeneration and the retinal complications of AIDS.

Myriam Gorospe, Ph.D. Dr. Gorospe is a research geneticist with the Institute on Aging of the National Institutes of Health in Baltimore, Maryland. She is VHLFA's Director of Research, accepting and reviewing applications for research grants awarded through the VHLFA. Having become interested in VHL because she has relatives with VHL in Spain, she translated the *VHL Handbook, Your Family Health Tree*, and many newsletter articles into Spanish, has been the key communicator with families and physicians seeking VHL support in Spanish language, and has been instrumental in the expansion of VHLFA services in Spanish.

Fabian Fonseca Guzman, M.D. Dr. Fonseca was born in Bogota, Colombia. He received his medical degree from the Juan N. Corpas Medical School in Bogota, Colombia, and completed a residency in Surgical Urology at the University of Costa Rica. His presentation is derived from his Ph.D. dissertation.

Joyce Wilcox Graff, Editor, VHL Family Forum. Ms. Graff is one of the original founders of the VHL Family Alliance. She served six years as Chairman and Co-Chairman of the Board of Directors, and was named Founder Emeritus in 1999. She was reelected to the Board in 2000 and serves as Chairman of the Board, Editor and Chairman of the Clinical Care Committee. With her late husband and her son Damon she has lived and worked with VHL since 1962. She edits the Handbook, the Newsletter, and the VHL website. An expert in electronic messaging, she is currently Vice President and Research Director in the E-Business Infrastructure research area at the Gartner Group, the world's leading high-technology advisory firm, based in Stamford, Connecticut.

Elson Haas, M.D. Medical Director, Integrated Medicine, Preventive Medical Center of Marin, San Rafael, California Dr. Haas has been in medical practice for over 25 years and was instrumental in the development of the field that he has termed Integrated Medicine. After graduation from the University of Michigan Medical School in 1972, Elson moved to Northern California where he received additional training. After an internship, he began further studies in many health-related fields -- Nutrition, Herbology, Oriental Medicine, Exercise Physiology, Body Therapies, and Mind-Body Medicine. He is the founder and director of the Preventive Medical Center of Marin, an integrated health care facility in San Rafael, California, where he specializes in Family and Nutritional Medicine, Detoxification, and Individualized Health Programs. His seven books on health and nutrition are practical guides that readers can use to learn to improve their own health. See his educational website at <http://www.elsonhaas.com>

Randall Hawkins, M.D., Ph.D., Department of Radiology, University of California, San Francisco. With an undergraduate degree in physics from Occidental College, Dr. Hawkins completed his medical education at University of California, Irvine. He did residencies in Medical Physics and Biomedical Physics at University of California, Los Angeles. Following an internship at the University of Southern California, he did a residency in radiology at USC, and in nuclear medicine at UCLA. Since 1993 he has been Chief of the Nuclear Medicine Program and Vice Chair, Department of Radiology; and Professor in Residence of Radiology and Bioengineering at the University of California Medical Center, San Francisco.

Peter Jackson, Ph.D., Assistant Professor of Pathology, Microbiology and Immunology, Stanford University Medical Center. Dr. Jackson graduated from Yale College with degrees in mathematics and studied theoretical physics before attaining his Ph.D. degree in biophysics at Harvard University. His graduate work at MIT's Whitehead Institute contributed to our biochemical understanding of how the Abl tyrosine kinase causes transformation in diseases like Chronic Myelogenous Leukemia. After post-doctoral work at UCSF and Harvard Medical School, Dr. Jackson joined the faculty at Stanford University School of Medicine in 1986. His laboratory works on the biochemical characterization of cell cycle and ubiquitin ligases, including the discovery of new ubiquitin ligase regulators and

characterization of small molecules that may lead to new drugs controlling this important class of enzymes.

Peggy J. Marshall

Mrs. Marshall is Chairman of the VHL Family Alliance. She is the creator and chairman of the 800 Committee, a group of five volunteers, all of whom have VHL, who rotate answering VHLFA's toll-free telephone number for the U.S. and Canada. Peggy has also chaired the Chapters Committee for the last seven years, which she is turning over to Kathy Braden this year.

Jay Platt

Jay Platt is a retired Marine Gunnery Sergeant. He was medically retired from the Marine Corp because of his VHL condition. In August 1998, Jay began his hike of 2,160 miles of the Appalachian Trail to raise funds for fighting VHL and Cancer. Jay completed his hike on January 23, 1999 raising over \$100,000 for the VHL Family Alliance. He is the President of It's All About Attitude, Inc. and author of the book *A Time to Walk*.

Thomas D. Rodenberg, Esq. Mr. Rodenberg is an attorney in Missouri who practices law in the area of civil rights. He has also advised numerous people on insurance issues, particularly as they relate to genetic conditions. Mr. Rodenberg has also been involved in litigation with insurance companies on the payment of benefits to those with VHL. His professional presentations include, 'Employers and the Law: What You Don't Know Will Hurt You', 1994, 'Insurance and VHL: What you don't Know can Hurt you' 1994, 'The Human Genome Project: Changing More than the Face of Genetics' 1994, and 'The Human Genome project: Kansas City, Missouri', 1999. Mr. Rodenberg is a Director of the VHL Family Alliance.

Oscar Salvatierra, Jr., Professor of Surgery and Pediatrics and Director of Pediatric Renal Transplantation, Stanford University Medical Center. Dr. Salvatierra is Professor of Surgery and Pediatrics and Director of Pediatric Renal Transplantation at Stanford University Medical Center. He was previously a member of the faculty at the University of California, San Francisco (UCSF) for 19 years, serving as Professor of Surgery and Urology and Chief of the Transplant Service. For the following three years before coming to Stanford, he was Executive Director of the Pacific Transplant Institute at California Pacific Medical Center. He received his B.S. degree from Georgetown University and his M.D. degree from the University of Southern California Medical School. He completed his residency in urology at the University of Southern California, Los Angeles County Medical Center and later completed a fellowship in transplantation at UCSF. He served in the U.S. Army Medical Corps for two years, including one year in Vietnam as a combat surgeon, receiving a number of decorations.

He has personally performed well over 2,000 kidney transplants, 600 of which have been in children. He has served as President of the American Society of Transplant Surgeons, President of the National Organ Procurement and Transplantation Network (UNOS), President of the International Society for Organ Sharing and President of the American Society of Minority Health and Transplant Professionals. He is President of The Transplantation Society (International) and has served on its Board of Directors since 1984. He has served as Chairman of the National Kidney and Urologic Diseases Advisory Board of the National Institutes of Health (NIH). He is on the editorial board of a number of journals, including *Transplantation* and *Transplantation Proceedings* and

Pediatric Transplantation. He has published over 240 scientific articles, including the following medical firsts: donor-specific blood transfusions; defining the hemodynamics of adult-sized kidneys transplanted into infants; and improved patient survival.

Dr. Salvatierra is generally recognized as the key lay figure nationally working with former Vice-President Albert Gore, in the enactment of the National Organ Transplantation Act of 1984, which developed a national system for listing of waiting organ recipients, equitable distribution of organs and a national Transplantation Registry. Dr. Salvatierra is the recipient of numerous honors and awards including a special recognition award by the UCSF Chancellor for "his distinguished service, his research contributions to advance clinical care and his national leadership role in patient advocacy." He has now embarked on the first complete steroid-free immunosuppressive protocol for pediatric kidney recipients.

Maria Shipton

Mrs. Shipton is Communications Director of the VHL Family Alliance. She oversees VHLFA's online discussion groups at groups.yahoo.com. There are discussion groups in English (vhlfa, moderated by herself and Gale Lugo); German (vhl-de, moderated by Gerhard Alsmeier of Germany); Spanish (vhl-es, moderated by Karina Villar, M.D., of Spain); and French (vhl-fr, moderated by Elaine Follansbee of New Hampshire). Her daughters Jamie and Jessika are helping at the registration table.

Robert Williams, M.S., M.D., Medical Director, Gould Medical Foundation, Tracy, California. Dr. Williams is a full-time primary care physician who has been a utilization manager for over ten years. He is board certified in both Internal Medicine and Pediatrics so he cares for both children and adults with VHL. He is a medical director with Sutter Gould Medical Foundation, in charge of Utilization Management. He has recently completed a three-year term as Chief of Staff of Sutter Tracy Hospital in Tracy, California. Dr. Williams completed his medical degree at Wright State University School of Medicine, Dayton, Ohio, and did affiliate training at Cleveland Clinic and Case Western Reserve University School of Medicine. He also practices sports medicine, and chairs a yearly symposium on Sports Medicine for Coaches.

Our Thanks to all the many volunteers
who made this event possible, including:

Kathy & Andy Braden
Dawn Cerf
David Irving
Peggy & Don Marshall
Selina McCusker
Rachael Morgenstern
Barbara Pedrick
Jamie Shipton
Jessika Shipton
Maria Shipton
Leslie & Bruce Trela

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helped others to come:

The Family of Frank Warren Graff
Armand & Lisette Rodriguez
Bill and Judi Scheitler
Hyman & Marjorie Weinberg Foundation
Harry and June Wilcox
National Institutes of Health Public Health Service Grant

Join us next year . . .

Fifth International Symposium on VHL
Padua, Italy, 2-4 June 2002

Ninth International Conference on VHL
Cleveland, Ohio, July 2002

Probable future sites . . . can you help?

2003 in New York
2004 in Texas

Contact us any time . . .

VHL Family Alliance

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