

Thoughts on the new U.S. Health Care Law

By Joyce Wilcox Graff

The process of getting this new law through Congress showed us the worst side of politics. People sometimes compare the process of making laws to the process of making sausage. Even if you like sausage, you probably don't want to look too closely at the process of making sausage – it's bloody, messy, and if you know too much about it you might never want to eat sausage again.

Nevertheless, we need healthcare reform, and we are finally taking action.

At our February meeting in Memphis, Tennessee, our speaker, Dr. Robert A. Sanford, one of the leading neurosurgeons in the Mid-South area who has treated people with VHL for more than 30 years, began by pleading with us to work for healthcare reform because half of the people he sees who have VHL don't have insurance and can't get it. While he has frequently done surgeries without charge, that doesn't mean there is no cost to the patient – there are still charges for the operating room, the imaging studies, the radiologist, the anesthesiologist – enough to cause you to lose your house. We talked with the five medical professionals who joined us in Memphis about how we might improve diagnosis and treatment of people with VHL in the area, and it came down clearly to one thing – everyone needs access to preventive care. You can't get a diagnosis of VHL without a primary care physician and regular care.

With a condition like VHL, emergency room care is not good for your health. Emergency rooms are for urgent care, like accidents. People without insurance have come to rely on the policy of federally-funded hospitals to take in people through emergency who do not have insurance. But that means that you have to wait until your situation is very serious before you can present yourself to an emergency room. If you go in for headaches, they will give you aspirin and send you home. If your situation is critical, they will probably do an MRI and the required surgery. But will that surgeon know enough about hemangioblastomas to do a good job? Will you

survive? And will you wake up whole or with deficits? In order to manage VHL successfully you need proactive preventive care.

Studies show that people who do not have insurance coverage do not go for preventive care. In the case of breast and prostate cancer, advances in the survivability of these cancers is primarily due to early detection. Still we see that the presence or absence of insurance makes a big difference in the utilization of available screening tests. [See Figures 1 and 2.] According to the most recent available data, 60% of women with insurance had a mammogram within the previous two years, while 42% of uninsured woman had never had a mammogram at all. The differences are even greater for men: while 40% of men with insurance had had a PSA test (a simple blood test) within the previous two years, 62% of uninsured men had never had a PSA test at all. Although screening tests are not perfect, they can play an important role in the early detection of dangerous cancers. The failure to detect lethal disease early on is not only measured in suffering and earlier death, it also drives up the cost of health care borne by the public. When a person with no insurance has advanced cancer (detected late), it is the American taxpayer who pays their much higher bills. How much better for all of us to find

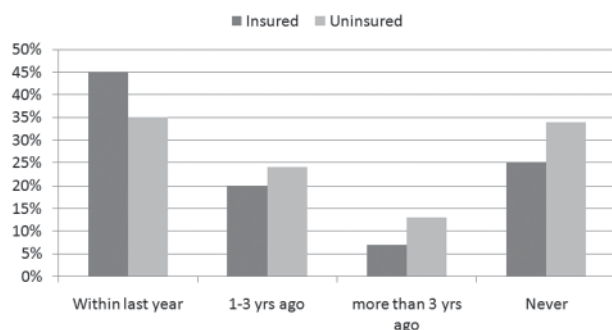
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Figure 1: Time Since Last Mammogram

Female workers, age 30-64, by insurance status



Source: Agency for Healthcare Research and Quality 2005 Medical Expenditure Panel Survey.

dangerous cancers at earlier stages, remove the tumors and save lives.

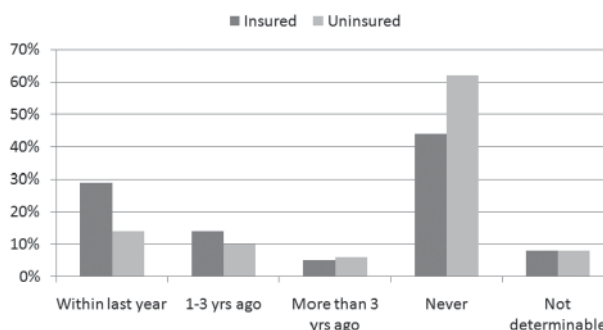
I have had the privilege of traveling to 26 different countries and visiting with people with VHL in those countries. It has given me a chance to see VHL through the eyes of different health care systems and medical cultures. The most striking difference for me has been that in countries with health care for all, the health care system has undertaken to keep people healthy, in the workforce, and paying taxes for their entire lives. They take the long view – not the short-term bottom-line view that most insurance companies in the United States have traditionally taken. Yes, they will pay for another MRI this year because it will lower the lifetime cost of managing this person's health. Even seen in monetary terms, it is clear that this approach will keep all of us happier and healthier throughout our lives.

Finding issues earlier means that younger people in particular need careful preventive care. More than 30% of people between 19 and 26 do not have health insurance. [See Figure 3] Why? Because they generally fall off their parents' family plans at age 19. In a first job they are often paid lower wages and may not even be offered insurance, or may not feel they can afford it. And yet this is the age group where VHL issues generally arise and are most prevalent. This is the age group that needs the most careful monitoring to preserve their health and function for the rest of their lives.

The new U.S. Health Care law as passed is a start. It is not perfect by any means, and there is a great deal of work to be done just to get the current law implemented. According to Dr. Risa Lavizzo-Mourey, President and CEO of the Robert Wood Johnson Foundation, which has been studying healthcare in the United States for more than 40 years, "The new law meets core principles for coverage set down by the Foundation and offers the

Figure 2: Time Since Last PSA Test

Male workers, age 30-64, by insurance status



Source: Agency for Healthcare Research and Quality 2005 Medical Expenditure Panel Survey.

country the opportunity to improve the health of our people."

There are several things in it that will make a huge difference for families with VHL, beginning this year.

1. Consumer protection to keep insurance providers from imposing lifetime spending caps, or arbitrarily dropping people from coverage when they are sick.
2. Coverage for children to age 26 on their parents' family plans. Some plans (notably UnitedHealth, Kaiser and BlueCross) have already made this change, others will follow between now and September 2010.
3. Children can no longer be denied coverage due to a pre-existing condition or DNA status. Implementation for adults will be gradual over the next few years, fully implemented by 2014.
4. By June 2010, each state must have a "high-risk pool" which will provide health insurance to people who cannot afford insurance premiums either because their income is low or because the rates they are offered are too high to be affordable.

In some states insurance companies are raising their rates now while they can, before the new controls go into effect in 2014. There is work going on in Congress to provide impetus for the states to regulate insurance rates if they do not already do so. If health insurance rates in your state are rising – in some cases by 30-40% in one year – you should speak with your elected representatives to let them know what this means to you. Some of these increases are for everyone, but in some cases they are attempts to make insurance unaffordable for people with serious health issues. Do not let this happen to you. There are new protections even in the current law – be sure to take advantage of these protections

and keep yourself and your family insured.

What does this mean to me in my state?

Each state is responsible for implementing the law according to the federal guidelines. There are two primary websites which give you the best up-to-date information about where to go, who to ask, and what to expect in your own state.

<http://www.covertheuninsured.org> sponsored by the Robert Wood Johnson Foundation. On the homepage of this site there is a map where you can choose your state. For each state there is a document that describes your options for access to health care and insurance. Check here first.

<http://healthreform.gov> has a map with updated reports by state of the changes already implemented in each state and how to contact the services you need.

<http://familyvoices.org> has a rich set of resources for families caring for a child with special needs. This broad definition includes children with a broad range of conditions or chronic illnesses such as cerebral palsy, developmental delay, ADHD, depression, asthma, and von Hippel-Lindau, as well as children who develop a significant medical problem that is expected to last at least twelve months. They also have a listing by state of the Family-to-Family Health Information Centers (F2F HIC's) that will help you access the services and resources you need in your area.

Comparative Effectiveness Research

Let me say a word about comparative effectiveness research (CER), since this is also a phrase that has been used and abused in the media. For all conditions little is known about which treatments work better (or less well) for people in particular circumstances. The Institute of Medicine (IOM) has been charged with doing research to determine the comparative effectiveness of different

therapies. The IOM is not a government agency. It is an honorary society of top physicians and researchers, like the National Academies in England or France. Doctors are elected to the IOM by their peers, to honor their achievements.

Today, the information we have comparing treatments generally comes from the pharmaceutical companies, or from those who are trying to sell you something. As one simple example, what is the relative effectiveness of the various anti-depressants versus exercise, yoga, or camomile tea? If your doctor prescribes 30 minutes of walking three days a week, is that to save your insurance company's money? Or is that to save you the potentially serious side effects of an anti-depressant pill? Read that list of potential problems on the label, and you decide.

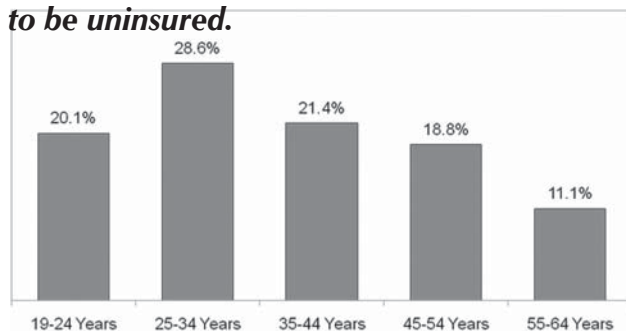
One of my favorite examples is from a cousin of my husband's who is a retired dairy farmer in Sweden. She has a prescription from her doctor to go to water aerobics three times a week at the local public swimming pool, to keep the arthritis in her knee from worsening. A knee replacement is serious surgery with a difficult rehabilitation for a 70-something lady. Water aerobics feels good, is a lovely social outlet, helps keep her fit altogether, and therefore helps her avoid depression, diabetes, and a whole number of other potential issues. A knee replacement and rehabilitation can cost as much as \$100,000 in the United States [see Note]. How many people could that payer send to water aerobics for how many years for \$100,000?

So yes, in part CER is about saving money. But more than that, CER is about keeping us all healthier and avoiding the dollar cost and the human cost of illness by simply avoiding illness, or avoiding complications, and prescribing the optimal therapy on the first try. And the legislation has been carefully written to make sure there is provision for people with rare disorders that may not fit the "usual" model. While one remedy may work well for most people, it should never be the "only" way to do things, as there will always be exceptions. People with asthma may need special handling, or a drug may be more or less effective for people with one additional genetic trait. But it can only benefit us all to have ways to collect information about outcomes, and open discussions about the pros and cons of different approaches – not only about one drug versus another, but about different strategies too.

Note: Estimate from Paul Brough, CEO of Pinnacle Health, a provider of employee healthcare insurance to employers. See *Powerful Patient*, 2008 week 37, "Medical Tourism", <http://tinyurl.com/pptourism>

See interview with Tony Coelho, Chairman of the Partnership to Improve Patient Care (PIPC), *Powerful Patient* 2010 week 3, <http://tinyurl.com/ppeffective>

Figure 3: Adults ages 25-34 are more likely to be uninsured.



Source: Estimated by SHADAC* from the Current Population Survey Annual Social and Economic supplement, 2008. * The University of Minnesota's State Health Access Data Assistance Center (SHADAC) is funded by the Robert Wood Johnson Foundation

Selecting Treatment Options

Reported by Joyce Graff

On April 23, 2010, I attended a conference on Benefit-Risk Considerations in making drug Regulatory Decision-Making, co-sponsored by the U.S. Food and Drug Administration (FDA) and the New York Academy of Sciences.

There were twelve very fine presentations from many different perspectives – FDA regulators, doctors, scientists, pharmaceutical companies, consultants, and even patients, from the U.S., Canada, and Europe. It all came down to a few essential criteria – define “benefit” and define “risk”.

Dr. Nananda Col from the Maine Medical Center gave us a glimpse into the “informed decision making” that she goes through as a physician. She used the example of recommending a course of action for a patient with osteoporosis. What should she prescribe? What are the pros and cons of each of the medications on the market? What is the easiest way for a physician or a patient to obtain this information? On Lowe’s or Home Depot’s websites you can select two or three candidate refrigerators or dishwashers and ask them to compare them for you – build a grid that shows you at a glance the characteristics of each, laid out in a similar way for easy comparison. No such tool for drugs. She went to WebMD, HealthCentral, and a variety of other websites and found articles about each of the many possible therapies, but nothing that would easily compare them. There is a convenience factor -- What is the most convenient way to administer the drug for this person (as a pill, an injection, an infusion, once a day/week/month/year)?

Since most of the drugs have very similar benefits (reduce the possibility of bone breakage), the real job is to choose among the various risks – for this patient, are we willing to accept an increased risk of heart attack, blood clot, stroke, cancer, stomach ulcers? It would be helpful to have statistics to indicate the level of risk (2% or 20% or 60%?) of each of these things, or whether people with a specific set of characteristics were at greater or lesser risk for these negative consequences.

Dr. Col asked in particular that the FDA provide a mechanism for reporting outcomes so that better information can be collected on the adverse events experienced by people taking any drug. This information is currently held by the pharmaceutical companies, and is often downplayed in the drug information fact sheets. “Blood clots have been reported” is not as informative as information about what percentage of people with a history of what kinds of health issues experienced problems. She feels that the government is in the best position to

Nananda Col, MD, MPH,
FACP, Director of the
Center for Outcomes
Research and Evaluation
at the Maine Medical
Center Research Institute,
Portland, Maine



do this, since no one else can be relied upon to be truly neutral – the medical resource sites gain their revenue from the drug manufacturers, which gives them a certain bias toward a drug-based solution (rather than simply exercise and Vitamin D), and potentially toward a particular client.

Until that happens, she suggests that patients should read the fact sheet that goes with the drug, and ask the doctor or the pharmacist to explain anything that is unclear. If the patient sees something worrisome in the fact sheet, it is best to discuss it with the doctor.

... define “benefit”

... define “risk”

There are no perfect drugs with all benefit and no risk. Every medication comes with a certain level of potential harm. We choose to accept the risk in order to gain the benefit. But each doctor and patient must weigh the possible benefit against the risk and decide ... in this situation, with this patient, and this person’s total state of health, is the possible benefit to be gained worth the potential harm? These are never easy questions, there is always a great deal of uncertainty – both around the benefit and around the risk. Will the full benefit be achieved? Will any of the possible risks ever occur?

We are all working to reduce the uncertainty and improve our ability to predict both the benefits and the risks. This is true of all drugs, and will be critically important as VHL enters the Brave New World of drug therapies for VHL tumors.

Dr. Gladys Glenn of the U.S. National Institutes of Health reminds us of two things we need when using any drug that is new to your body:

(1) Close monitoring early (blood & urine tests; rule out new symptoms) during the initial phase of the treatment, so as to identify early any developing adverse effects.

(2) Early assessment to determine anti-tumor activity (using imaging and biomarker(s)).

Be well . . . and be a Powerful Patient!

Meet me in St. Louie, Louie
Meet me at the ... VHL Conference!
June 19, Saturday
8:30 am - 5:30 pm
Marriott Union Station Hotel

Genetic Non-discrimination

*from Debra Collins, MS, CGC, Genetic Counselor,
University of Kansas Medical Center, Kansas City*

As work on the human genome proceeded, there was worldwide recognition that DNA information could be used for great good, and it could also be misused. Many countries throughout Europe and in Australia, New Zealand, and Japan, have already taken action to establish basic legal protections that will enable and encourage individuals to take advantage of genetic screening, counseling, testing, and new therapies that will result from the scientific advances in the field of genetics.

In the United States, the Genetic Information Non-Discrimination Act (GINA) was passed in 2008, to be implemented by the states by fall of 2009. GINA prohibits discrimination on the basis of genetic information with respect to health insurance and employment. It also prevents health insurers from denying coverage or adjusting premiums based on an individual's predisposition to a genetic condition (before any medical issues arise), and prohibits employers from discriminating on the basis of predictive genetic information. GINA stops both employers and insurers from requiring applicants to submit to genetic tests, maintains strict use and disclosure requirements of genetic test information, and imposes penalties against employers and insurers who violate these provisions.

The website of the National Conference of State Legislatures provides a table with a current summary of state laws pertaining to the use of genetic information in health insurance. Restrictions on the use of genetic information in health insurance may address the use of genetic information in individual insurance, group insurance or both. These laws may restrict health insurers from engaging in certain activities, including using genetic information to determine eligibility or set premiums, requiring genetic testing of applicants, or disclosing genetic information without consent. The states with genetics and health insurance laws listed in the table also may have laws related to other genetics policy issues, such as genetic privacy or genetic discrimination in other settings. The legislature may have addressed these issues in conjunction with or separately from genetics and health insurance.

<http://www.ncsl.org/default.aspx?tabid=14374>

St. Louis Conference

Invitation from Amy Williams, Co-Chair Missouri

Have you ever had the feeling of being in this battle alone, wanted someone to talk to, hug and share experiences with who truly "gets it"? Well, your desires can become a reality in June. Consider joining us June 19, 2010, in St. Louis for a Patient/Provider meeting from 8:30 am-5:30pm!!

This meeting will allow you the opportunity to meet other VHL patients and their families. You will also have the opportunity to hear some wonderful speakers as they address VHL issues.

The conference registration includes the meeting space, handouts, group lunch, and snacks during the day. Discounts available before May 27, but we will welcome you, even at the door! Register on the web, or on page 10.

Cardinals Baseball!

We have arranged for a block of tickets to the Cardinals Baseball game vs. Oakland on Friday evening June 18 before the conference. Tickets are behind third base. They are \$40 apiece (regularly \$45) so we can all enjoy the ballgame together and get to know one another.

Highlights from the agenda:

Dr. Theresa Deshields from Barnes Hospital and Washington University will speak on dealing with the stresses and strains of living with chronic illness.

Dr. Arun Singh from the Cleveland Clinic will speak on eye issues in VHL

Dr. James Gnarra of the University of Pittsburgh will update us on VHL Research, and Dr. Rachel Giles of the University of Utrecht will talk about her research on VHL using zebrafish, funded in part by the VHLFA.

Dr. Adam Kibel of Barnes Hospital and Washington University will speak on kidney issues in VHL

Sarah Nielsen, a genetic counselor from the University of Pittsburgh, will share her research on two large VHL families in Pennsylvania that can be traced back to the 17th century.

Dr. Ram Srinivasan of the U.S. National Institutes of Health will share with us the progress of drug development and testing for VHL and some clinical trials opening soon at NIH.

And Amy Riter, Miss Wheelchair Ohio 2010, will share her own VHL story and lead a Round Table discussion among the attendees in the afternoon.

We can't wait to see you!

Your conference team: Brian Martz, Doris Haarmann, Jodi Hopewell, Kate Paige, Amy Williams, and Mary Lou Linn.

Revising the Handbook

The 2005 edition of the Handbook is still the current version. The most important change since that edition is our address: we moved in 2006 to 2001 Beacon Street, Suite 208, Boston 02135. The website, telephone numbers, and e-mail addresses are all the same, but the postal address is different. The post office no longer forwards mail sent to the old Clinton Road address, so please make sure you have changed your records.

There is a 2009 edition of the Handbook at Amazon.com which updates our address but does not make any significant changes to the text.

We are currently working on updating the text, with a revised edition slated to appear in 2011. Since the Handbook is now in 11 languages, the changes planned for this edition will be modest, and will not be a full rewrite.

Our goals for this year's revision are:

- enhance the pancreas and ELST sections
- review the screening protocol and get agreement world-wide, paying special attention to radiation, gadolinium, compliance and cost.
- update the Research section, talk about the new drugs coming out and where to get clinical trials info
- update the References to include new key articles

At the 2008 Symposium in Denmark we heard some very helpful reports evaluating the effectiveness of the screening protocol in affecting treatment decisions, and the challenges of getting people to show up for scans even when cost is not a factor.

We will appreciate hearing from you – your questions or concerns about anything in the

Handbook, and your impressions of “what’s missing?” – what would you like to hear about in a future Handbook?

Again, the primary purpose of the Handbook is to inform you and your primary care physician about what VHL is, how it behaves, how to screen for the various issues that might arise, what symptoms to watch for, and the strategies that we have found work best in considering treatments.

We moved in 2006 to

**VHL Family Alliance
2001 Beacon Street, Suite 208,
Boston MA 02135-7787 USA**

*The post office no longer forwards
mail from the Clinton Road address.*

We need to hear from patients and physicians how this is working – what else do you need from us to support you in doing it right on the first try? How can we support you in maintaining health and quality of life?

We need to hear from you!

With this issue, we have provided an envelope prepared for business reply mail - we pay postage!

Please send us your VOTE for the slate of new Board members

And your FEEDBACK on the Handbook

Need more copies? We are happy to provide you with as many copies as you need of the 2005 edition, FREE while supplies last.

关于 VHL 病的知识

**The VHL Handbook
What you Need to Know about VHL
now in 11 local languages!**

वी एच एल (VHL) : समस्त जानकारी ही लाभकारी

Manuel en français

VHLについて知っておくべきこと

Folleto en español

Congratulations to Spain and Argentina and India on their beautiful new local versions of the Handbook! Special thanks to Dr. Karina Villar and Dr. Ashok Pillai for making these happen!

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Priorities Survey

We are always re-examining our priorities at the VHL Family Alliance, to make sure we are focusing on the things of greatest interest and benefit to our membership -- that's YOU! All our family members, friends, physicians, and researchers are valued members of this Alliance. We would appreciate your taking 10 minutes to fill out this survey so that we can add your voice to our thinking.

The easiest way is to do it online at <http://www.surveymonkey.com/s/B8MJC9>

If that doesn't work for you, please do it here, in print. We have enclosed a business reply envelope that will carry your ideas back to us. Please be sure to include

- ☐ your VOTE for the new directors
 ☐ your MEMBERSHIP renewal and donation to research
☐ your FEEDBACK on the Handbook
 ☐ as well as this SURVEY.

Feel free to use as much paper as you need to explain your ideas. -- *Thank you!*

1. Please tell us what point-of-view you bring to this survey. (check all that apply)

- ☐ I have VHL myself
 ☐ I am a medical professional
☐ One of my family members has VHL
 ☐ I am a physician
☐ One of my friends has VHL
 ☐ I am a researcher working on VHL
☐ I support the cause with my donations
 ☐ I am an active volunteer with VHLFA

2. As we grow and set priorities for the coming year, we would like to know what YOU think we should be focusing on. Here are some of the things on our current list. Of the items listed, how important is each of these to you? If your item of interest is not listed, please add it at the end.

	Most important	2	3	4	Least important
Supporting legislative changes in the U.S. and Europe that will help people with VHL and other rare diseases					
Raising money to fund research					
Finding a drug that will control brain and spinal tumors					
Providing information and referral so patients can find better care					
Helping doctors recognize VHL so they will treat people correctly					
Helping patients learn how to advocate for themselves with doctors					
Finding natural or complementary remedies that will control tumors					
Providing emotional support to patients					
Helping doctors learn the best ways to treat people with VHL					

3. What do you think is the best way (or ways) for us to influence the rate of diagnosis -- how can we help more people get a timely diagnosis of VHL so that they and their doctors understand what they are dealing with?

4. Finding a natural or complementary remedy is hard since pharmaceutical companies are not motivated to spend the money to run a clinical trial to determine their effectiveness. If

you were in charge, how would you go about finding an herbal remedy that might keep tumors under control?

5. What do you feel is the best way(s) for VHLFA to raise money to fund research projects?

6. What is the best way to help people get the right treatment on the first try? Please help us learn from your own experiences.

7. Have you ever participated in a clinical trial of a new drug for VHL or another condition?

8. If you considered participating in a clinical trial and chose not to go forward, please tell us what your considerations were. What held you back?

9. If you did sign up for a clinical trial, please help us understand your thinking and your experience. What motivated you to go forward? How did the experience go?

10. In thinking about clinical trials, have you tried to find information from others who have been in a clinical trial for this or another drug? Did you ask others in your community? People on the internet? Contacts through the hospital or the team sponsoring the trial? Was that input helpful to you?

11. What is the best way for us to support research? (share tissue? share medical histories and update them regularly? etc)

12. What do you feel is the best way(s) for us to support patients and families?

☐ Telephone hotline, always answered by a human being

☐ Telephone hotline, usually answered by a human but with quick return of messages

☐ Live online "chat"

☐ E-mail "hotline"

☐ Online support forum like <http://vhl.inspire.com> where I can post a message and within a day or two get an answer from someone who has had a similar experience.

13. Do you feel that VHLFA has helped empower patients and families in some way? Please help us understand what we are doing right!

14. We are too small to do effective lobbying by ourselves, so we have joined the efforts of other genetic and rare diseases in their lobbying efforts with the American and European governments. What activities do you think we should be involved in? If this is an area that interests you, we would appreciate your getting involved!

☐ We are members of the National Organization for Rare Disorders (NORD) and its European counterpart (EURORDIS).

☐ Volunteers from VHLFA participate on committees in NORD and Genetic Alliance and similar organizations in Germany and Denmark to influence legislation affecting us.

☐ As a member of the Partnership to Improve Patient Care VHLFA helped to shape the final wording of the legislation on Comparative Effectiveness Research, to insure that people with rare diseases would have access to appropriate treatments.

15. Over all, what do you think is the one most important thing for us to focus on in the coming year? If you were running the show, what would you want to do first?

16. What is the best way to communicate with you?

☐ paper mail only ☐ e-mail me the summary and I'll read or print it online

17. Would you like us to follow up with you? If so, please supply a telephone number of e-mail address where we can reach you. -- *Thank you!*

Candidates for Board of Directors, VHLFA

Please return your proxy vote or come to St. Louis to cast your votes for these three candidates



☐ Jeanne McCoy

Jeanne McCoy, Greenville, South Carolina, candidate for re-election

Jeanne McCoy is an active community volunteer, serving the Junior League, the American Cancer Society, the Greenville County Legal Auxiliary, and her children's school. A former French teacher with degrees from Wake Forest and the University of Georgia, Jeanne is now a stay-at-home mother to her three children. Her husband, Ellison, is a labor and employment law attorney. Jeanne was diagnosed with VHL in 2003, less than a year after her mother's diagnosis. Her grandmother lived to the age of 82 despite suffering blindness and other ill effects of VHL. Since her diagnosis, Jeanne has had two neurosurgeries and two kidney surgeries. Jeanne's personal and family experience with VHL have led her to be a vocal advocate for those whose lives have been impacted by VHL and cancer in general.

During her first term on the VHLFA Board Jeanne also served as President of the Junior League. She has gained a great deal of practical experience in working with Boards which she is looking forward to sharing with the VHLFA Board. Jeanne intends to use her board membership as an opportunity to develop additional outreach programs regarding VHL.

John Wallace, M.D., Emergency Medicine, Mahattan Beach, California



☐ John Wallace, pictured with wife Karynne and daughter Karli

My wife's and my avocation to the VHL cause began last August with our 7-year-old daughter's diagnosis of VHL. This will be a lifelong journey. We have not yet begun to scratch the surface of the support services offered by the Alliance to all in the "family". These support services are an incredibly important aspect of what the Alliance offers. In addition, fruitful research in biochemistry, medical devices/equipment and treatment/screening programs are the key to what the future holds for anyone who carries the genetic makeup. None of the previous will be possible without successful fund raising that reaches beyond the green shoot level of our immediate family. Under Joyce's leadership and with all of your participation, a lot has already been accomplished and yet there clearly is much more to do.

I currently juggle my clinical duties as an "ER pit Doc" with business duties as a managing partner, other hospital duties, as well as all those activities that constitute all of our lives including managing my daughter's illness, screening program and deciding where and by whom she will be followed in the future blended with the attempt to assure her a "normal" childhood. Nonetheless I can certainly commit to Board teleconferences during the year, and I have great interest in collaborating with Joyce regarding medical research to try and push the current state of knowledge and treatment forward. My interest and passion for the cause will not change.

Bill B. Scheitler, LeMars, Iowa, candidate for re-election



☐ Bill Scheitler

Bill and his wife Judy, a registered nurse at Floyd Valley Hospital in LeMars, have three children. Son Bill and his wife Jane live on the family farm with their three children; Richard and his wife Jennifer live in Los Angeles, California; Jodi and her husband Matt live in LeMars, Iowa, with their two children. Bill is president and CEO of S&H Marketing in Remsen, Iowa, an agricultural consulting firm. Bill has traveled throughout this country and approximately 20 other countries representing the United States, the State of Iowa, and the Cattle industry.

"Communication, education and research are the three areas of focus that I believe are extremely important to the VHL Family Alliance. These areas of interest need to be addressed throughout this country and the world community. My daughter's two surgeries this year underscore the need for less damaging ways to stop tumors. We need to facilitate progress in any way we can. There is always more to be done." Bill looks forward to continuing to serve the VHL Family Alliance.

Membership & Registration

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Home phone: _____ Work phone: _____

E-mail: _____

Preferences:

☐ I would like to receive occasional alerts via e-mail ☐ I want to Go Green! (newslettter via e-mail)

Yes! I want to be a member!

Annual dues: \$25 per mailing address (\$35 outside U.S.* credit card preferred for international payments) \$ _____

Yes, I want to help fund another research grant! My additional contribution: \$ _____

☐ Please charge \$_____ to my card monthly for _____ months

☐ Please renew my membership annually until I change it

☐ *Children's book full color, illustrated - member price \$6.50, non-member price \$12.99* \$ _____

☐ *Go Green!* Please send all materials by e-mail to reduce costs and save the earth too!

Register for the St. Louis meeting, 8:30 to 5:30 pm, Saturday, June 19:**

☐ One registration (includes lunch and breaks) @ \$85 if booked by May 27 (or \$95 thereafter) \$ _____

☐ Registration for two people (includes lunch and breaks) \$155 before May 27 (\$175 after) \$ _____

___ Ticket(s) for St. Louis Cardinals vs. Oakland, Friday evening June 18, while seats available, @ \$40 ea \$ _____

** Make your own Union Station Marriott reservations, by May 27 to get group rate \$129 (regularly \$169)
phone Marriott reservations at 314-621-6262 or 800-228-9290

☐ VHL Handbook, Kids' Edition Members, \$6.50 ea, Non-Members \$12.99 each \$ _____

☐ VHLHandbook, international edition Members \$6.50, Non-Members \$12.99 each \$ _____

Postpaid to US addresses. Outside US, please add \$5 for shipping.

A Gift to the VHL Family Alliance is a living gift of love - Sent with Hope for a Cure!

Special gifts total \$ _____

Remember VHLFA when you want to celebrate an occasion or a loved one (minimum \$10 per honoree)

☐ in Honor of ☐ in Memory of _____

Acknowledgement card to be sent to: _____

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VHL Family Alliance

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Thank you!

International members - please make payment by credit card if possible

Banking fees to process checks in non-US funds are now \$35 per check.

Canadians, please send checks to: Canadian VHL Family Alliance, c/o Jill Shields,

VHL Awareness Month

May is VHL Awareness Month. There are a number of activities scheduled for May and June to raise awareness of VHL in our local communities, and to raise money for ONE MORE RESEARCH GRANT this year!

In this newsletter, or on the web, you will see ideas that other people are implementing in their own communities. Please add your own creative thinking, and change your own little part of the world.

Hillary Gokey is donating to VHL half the profits from her new book about families using laughter to defuse stress. See <http://tinyurl.com/pplaughter>

Ann Riley performed on a local television station and spoke about her son's experience with VHL.

The Argentine affiliate is meeting for the first time on May 7 in Buenos Aires.

The Massachusetts Chapter will stroll around Jamaica Pond on May 16.

The Angotti family will host a pancake breakfast May 22 in Florida.

A reception will be held at the Massachusetts State House on May 25 to present a declaration from the Massachusetts Senate honoring VHLFA.

The St. Louis Cardinals will welcome VHLFA to their game on Friday night, June 18.

Matt's friends are hosting a golf tournament in Massachusetts on June 28.

Please tell us what you will be doing!

Write to development@vhl.org

Single Married Moms (or Dads)

often find themselves in awkward situations where it sure would help to have another set of hands! Hillary Gokey has collected some delightful stories, with great examples of how laughter can get you through some pretty frustrating times! See Joyce's conversation with Hillary on the Powerful Patient, at <http://tinyurl.com/pplaughter>

Cleaning for a Reason

Submitted by Fran Mott, Michigan

If you know any woman in the United States currently undergoing treatment for cancer (any type of cancer, including VHL), she may be interested in a cleaning service that provides FREE housecleaning one time per month for four months while she's in treatment. See <http://www.cleaningforareason.com>.

Join us in Rio de Janeiro!

We cordially invite you to take part in the 9th International Medical Symposium on VHL, which will be held from October 21 to 24, 2010, in the city of Rio de Janeiro, Brazil.

The 9th International Medical Symposium on VHL continues to be considered the premiere international meeting providing a diverse and unique opportunity for attendees to share, discuss and learn the latest advancements in von Hippel-Lindau disease.

It will also include a variety of educational opportunities such as paper presentations, debates, lectures, symposia and instructional course lectures. Lunch time hands-on workshops, posters and technical exhibits will also be offered at the symposium.

The symposium has been organized in one entire day dedicated to molecular and basic research, and the second day for clinical research. The VHL family Meeting will be held on the 3rd day, with the participation of VHL families from Latin American countries and all the world.

The meeting will be held in the Othon Palace Hotel on Copacabana Beach in Rio de Janeiro.

On behalf of the Organizing Committee we would like to welcome you to Rio de Janeiro and invite you to enjoy one of the most beautiful cities in the world.

José Cláudio Casali da Rocha, MD, PhD, Director of the Brazilian National Tissue Bank and Chairman of the Symposium



***Scientists, please submit
abstracts of talks you
would like to present at the
meeting in Rio. Please send
abstracts (in Word format) to
conf2010@vhl.org***

Getting help with digestive complaints

Question from the Facebook group: People in the Facebook group have been asking questions about VHL and pancreas growths. In particular, one member was wondering what type of doctor to see in the event that there are growths on the pancreas. There is the question of the tumors themselves, and there is also the question of how to handle the digestive complaints that often accompany pancreatic cysts and tumors.

Response: Great questions, and ones I am wrestling with for the new Handbook. Meanwhile, here's a rough answer and we can share more as we learn more:

Read both the Handbook section on pancreas and the two articles listed at <http://vhl.org/pancreas>

Even if there are only cysts, there may be some interference with delivery of the pancreatic enzymes that should be explored with a gastroenterologist or endocrinologist familiar with digestive issues. People with these issues often don't realize there is something that might be done about it -- they just think they have a crazy digestive system.

The best suggestion we have so far is to look for a gastroenterologist who treats adults with cystic fibrosis (CF). This is the kind of doctor who focuses on problems in the digestive system, and evidently

people with CF have similar issues. Read the doctor's resume on the internet before you book the appointment. You need someone who understands the mysteries of the intricate balance of digestive enzymes produced by this amazing organ, and who will work with you to find the right combination that improves your quality of life.

If solid lesions are suspected on imaging, they should see an endocrine surgeon. It is not easy to tell the dangerous lesions that need to be removed from the less dangerous ones that you can live with. In the U.S. I would suggest they see or consult with Dr. Steven Libutti; in Europe with Dr. Pascal Hammel. Both have expressed willingness to review scans and comment on cases. Some fees may be involved.

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Healthy Chocolate to Spread the VHL Story

by Lisa Steindel, Director of Development

The VHL Family Alliance is embarking on a new fundraising project. Beginning this summer, we will be distributing boxes of Healthy Xocai Chocolate for display at boutiques, offices, retail stores and businesses. The plan is to collect donations of \$10 for a packet of 6 delicious dark chocolate squares. Each display box will contain 20 packets, which should result in a donation per box of \$200.

Members and friends willing to display our Chocolates and willing to forward to us the resulting \$200 in donations, will not be asked to pay us for the box ahead of time, but we will ask you to make sure the proceeds are returned to us within 60 days.

We do believe that the Xocai Chocolate is delicious and that a lovely display (explaining a bit about VHL and the work of the Family Alliance) sitting next to the cash register at your favorite beauty shop or book store could be a great way to raise awareness and generate some much needed income.

We will be distributing the first batch of boxes at our Annual Conference in St. Louis. If you would like to place a box at your place of business or at your favorite neighborhood coffee shop, you will



Healthy Chocolate -- What could be better?

be able to take a box or two home with you from St. Louis. If you are not going to be able to join us in St. Louis but would like a box, please email or phone Lisa at development@vhl.org or 617-277-5667 ext 4.

The candy is delicious, the cause is important and the opportunity to "spread the word" is imperative as we try to invent new ways to tell our story and support our work. I invite you to think about places in your own community where this display might find a home. After all: it is "Healthy Chocolate" -- what could be better!

ED Search Committee

by Joyce Graff, Executive Director

The Board of Directors has received several applications from members of our VHL Family which are being reviewed as we speak. We have received a number of questions, which I will try to answer here. Please feel free to ask any additional questions of your own.

I am not leaving, though like everyone else I am getting old -- now an official Senior Citizen. I am working with the Board to do some responsible succession planning for me. I want to make very sure that the organization continues to be strong, long after I am gone. We have taken a close look at what I am currently doing for the organization and thought in terms of who we would need to continue those functions. In short, we feel that we will need three people to carry the work forward:

- a technical lead (since I'm the computer expert in the office)
- a business lead (filing paperwork with the IRS and the various states, managing personnel, and leading the fundraising)
- a "wellness" lead (working with the medical advisors, improving the Handbook, expanding the clinical care centers program, facilitating clinical trials) and recruit volunteers to understudy this role

Of the three, the "wellness" role is the most difficult to fill, and it's the one I love the best. So that's the one I would like to keep the longest.

The technical leadership is the easiest to fill with

contract services, and we have already found a very good technical support service for small businesses who are giving us a charitable price for their services.

The business leadership needs someone with passion for the cause, but not necessarily the depth of experience that I have with VHL per se. It might be a professional with experience in fundraising and non-profit administration, or it might be another person from a VHL family with good business experience who would love to step into this role.

For this reason we advertised the position first among our "family". Is there an experienced executive out there who would like to take on the challenges of building this organization? Who else might we find from among "our own"? We have also begun posting it openly.

Please know that we are looking for the "right person" -- not just anyone -- and that I am certainly not going anywhere. I will continue with the Alliance, focusing my energy more fully on the "wellness" side of things with the able assistance of Lisa Steindel in the "business and development" role throughout the transition, as long as it takes.

We -- the Board and the staff -- feel keenly our obligation to you, to every donor, and to the government authorities, to continue to provide the kind of professional leadership you have come to expect from us -- to provide service to every patient and physician, to support every volunteer who extends the reach of our services, to evaluate every research proposal, and to search for and report to you all the resources and advances that can possibly help you.

Hope

I had a very rough few months, in and out of the hospital with complications following my surgery. I could have told them if I had been right in the head that because I had a bilateral adrenalectomy years ago, when I'm sick I need a higher dose of replacement steroids. Oops, they forgot that.

For a while I really didn't see light at the end of the tunnel. But one day a woman whom I had never seen before came into the room and asked if I would like any chapstick lip moisturizer. With my parched lips from dehydration and me having left my chapstick at home, it was the one thing in the world I wanted at that moment.

I took it as a sign. I slathered that comfort over my lips and the comfort spread to the rest of my body. I knew then that I wouldn't be in the hospital forever, I wasn't going to die, and I would get better. It was only a few days later that they let me go home. Hope comes from the strangest places, but it is a very powerful medicine. - Amanda H.,

Vote for VHLFA!

GreatNonprofits is asking you to rate your favorite cancer-fighting nonprofits. The 2010 awards will be announced in August 2010. You can vote any time during the year.

We would very much appreciate your going there and letting them know what VHLFA means to you, and how we are working to fight cancer - not only through research, but in finding help today, and in managing life with VHL.

With your help, we are hoping that next year the VHL Family Alliance will be included in the top cancer fighting charities!

The contest is sponsored by GreatNonprofits, GuideStar, and Planet Cancer.

<http://www.greatnonprofits.org>

Thank you!

Our Thanks for donations from:

the thank-you list appears only in the print edition

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VHLFA Annual meeting, St. Louis, Missouri
Saturday, June 19, 2010

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unionstationmarriott.com, 800-410-9914

Be sure to say you are with the VHL
meeting to get our discounted room rate.

See agenda details on page 5

Registration: \$85 per person, or \$155 for two,
if booked by May 27. Register on page 10,
and make your own hotel arrangements.
Sign up for our block of tickets for the St.
Louis Cardinals versus Oakland on Friday
night, June 18, before the meeting.
Please see vhl.org/meetings for the latest
information.

Medical meeting English/Spanish: 9th International VHL Medical Symposium

Othon Palace Hotel, Copacabana Beach,
Rio de Janeiro, Brazil

Working group on Handbook October 22

Scientific meetings October 23-24, 2010

Patient meeting Sunday, October 25

The meeting will be translated for speakers
of English, Spanish, and Portuguese.

Scientific abstracts may now be submitted
to the conference chairman,
Dr. Jose Claudio Rocha, conf2010@vhl.org
additional details will be posted at
<http://vhl.org/conf2010>

3rd Annual Cure VHL Pancake Breakfast

Valrico, Florida, May 22

Beef O'Brady's, SR 60, Valrico, Florida
May 22, 8:00 AM

Sponsored by the Angotti family in
honor of Steven

It's Spring again! Time to

..Renew your Membership

..Vote for new Directors

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***..Help us spread the word
about VHL!***

See the pull-out in the middle