

## A Great Victory: Real Hope for Patients

*a note to VHLFA Members worldwide by Delphine Caiola, Paris, France, a member of Dr. Richard's staff*

I am delighted to report that Professor Stéphane Richard won the top prize in the category of cancer research in the Victories of Medicine 2006. This is a national competition among teams nominated by their hospitals for outstanding work in Medicine.

I am going to tell you a bit about the series of events in this memorable evening. We arrived at the Variety Theater in Paris for the ceremony. The team was seated on the stage. Our Guy (Guy Allegre, the patient advocate in Dr. Richard's group) was seated in the orchestra. Professor Richard, like the great "star" that he already is, arrived a little later. With all of us waving to get his attention, he appeared on stage. We all had a program with the names of the nominees. Oh, horrors! on page 11 the photo of Dr. Richard. Honestly and totally objectively, the photo was hideous and not at all flattering. It was taken when he was speaking. Clearly, looking down from our perch, we could see all his nervousness.

The cancer research category arrived at last. Three nominees, thus three short reports were shown on film. We all held our breath for the 30 seconds of the voting. And believe me, 30 seconds is a long time. Then the announcement of the results, "The winner is Professor ..." an interminable suspense. We all crossed our fingers and wondered if all the other nominees were also professors... (all this during 10 seconds) "... RICHARD"

And then, an explosion of joy. A real cheering section, a great joyous shout was heard. Professor Richard was applauded enthusiastically. And I admit that I spilled a tear or two. I thought of all of you. This victory is synonymous with a great recognition of our malady, for all of you and for the work of Professor Richard. He was very moved when he accepted the prize.

Afterward they had a little cocktail party. You can imagine of course that the Chief was kept quite busy with photos, interviews, and hand-shaking.

I hope that this victory will work to the benefit first of all of you -- families affected by VHL -- who are the real winners of this evening.



*Photo courtesy of J. J. Crampe*

There is a video clip of the event on the website. Even if your French isn't very good you can appreciate the tone and the excitement of this event.

The film tells the story of the pretty woman (Juliette) who has VHL, passed to her from her father. Dr. Richard explains the importance of a careful program of surveillance, and a whole-body approach to the problem.

After receiving the award he thanks his team of 15, and his 50 or so collaborators throughout the French-speaking world. "VHL is often relegated to the standing of a rare disease," he explains, "but what people don't realize is that VHL is also at the base of treatment of metastatic kidney cancer for people in the general population as well."

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On November 23, the Variety Theater in Paris was the scene of a television event honoring leaders in achievement in medicine from throughout France. [photo reseau-chu.org]

Dr. Stéphane Richard, a member of our Medical Advisory Board, has just won a very prestigious prize – Victories of Medicine. His submission: “A multidisciplinary approach to von Hippel-Lindau disease (VHL). From early diagnosis to targeted therapies: real hope for patients.” Professor Richard directs the Urological Service of the Institute Gustave Roussy, a the Hospital of Bicêtre, a southern suburb of Paris.

The selection of candidates was conducted in partnership among the Network of University Hospital Centers (CHRU), the medical commissions of the hospital centres, the learned medical societies, and the associations representing the various specialties. A prize would be awarded in front of a large audience to honor these initiatives in prevention, health information, or public health.

On Thursday the 23rd of November 2006, the Variety Theater in Paris rolled out its red carpet in honor of medical progress. More than 1000 persons representing the world of medicine were able to follow in great detail the 2006

panorama of therapeutic advances in the various categories: the war on cancer, against diabetes, against cardiovascular illnesses, surgery, specific technologies, and, for the first time, the quality of nursing care. To select the 7 winners among the 17 nominees, the 700 doctors present for the award ceremony elected by electronic voting the most outstanding innovations.

Over the past 15 years, Dr. Richard has assembled an excellent team and a group of some 50 collaborators throughout the French-speaking world to study VHL. They have published an impressive number of papers in French and in English which have expanded our knowledge of VHL and how to treat it. Through his efforts, France has one of the largest national databases of all people diagnosed with VHL in all of France, which has given us a unique population-based view of VHL. Even so, there are many more people without a diagnosis.

Pierre Regnault, mayor of the town of La Roche sur Yon in western France where Dr. Richard went to school, recounts in his “blog” a conversation with the poet Antoine Richard, father of Stéphane: “Mr. Antoine Richard, running into me at the opening of the department store Galeries Lafayette in Lyon Friday night, had reason to be proud. His son, Professor Stéphane Richard, a former student of the Edward Herriot College and Pierre Mendès-France High School, had just been elected one of the laureates of the Victories of Medicine. This prestigious prize honors Stéphane Richard for his work in cancer research. He is now director of the Oncogenetics Service of the Bicêtre Hospital and the laboratory of urologic oncology of the Gustave Roussy Institute in Paris. His work has allowed him to improve hope for life and quality of life for his patients. All our congratulations!”

Sources : [www.victoires-medecine.com](http://www.victoires-medecine.com),



Left to right: Sophie Gad (post-doc), Prof. Léon Olivier (former boss), Sandrine Lefèvre (former post-doc), Guy Allègre, Prof. Richard, Betty Gardie-Capdeville, Charline Ladroue (Thèsarde), Delphine Caiola (Lab Technician), Marie-Laurence (his wife), Professor Gérard Benoît (Urologist), Dr Nathalie Rheims (one of the managers of the Cancer Service of the Hospitals of Paris)

# Overcoming Life's Disappointments

*Excerpt from a new book (2006) by Harold S. Kushner, Author of "When Bad Things Happen to Good People"*

*Editor's Note: Dealing with VHL, we deal with a number of disappointments, beginning with the realization that we are not in control. Kushner offers some insights for how people learn to meet them with faith in ourselves and in the future.*

What happens to a dream deferred?  
Does it dry up like a raisin in the sun?  
— Langston Hughes, "Harlem"

In these lines, the poet Langston Hughes wonders what happens to dreams that don't come true. I wonder what happens to the dreamer: How do people cope with the realization that important dimensions of their lives will not turn out as they hoped they would? A person's marriage isn't all he or she anticipated. Someone doesn't get the promotion or the recognition he had set his heart on. Many of us look at the world and see two groups of people: winners and losers: those who get what they want out of life and those who don't. But in reality life is more complicated than that. Nobody gets everything he or she yearns for. I look at the world and see three sorts of people: those who dream boldly even as they realize that a lot of their dreams will not come true; those who dream more modestly and fear that even their modest dreams may not be realized; and those who are afraid to dream at all lest they be disappointed. I would wish for more people who dreamed boldly and trust their powers of resilience to see them through the inevitable disappointments.

History is written by winners, so most history books are about people who win. Most biographies, excluding works of pure scholarship, are meant to inspire as much as to inform, so they focus on a person's successes. But in real life, even the most successful people see some of their efforts fail and even the greatest of people learn to deal with failure, rejection, bereavement, and serious illness.

The lessons of this book will come in large part from examining the life of one of the most influential people who ever lived, Moses, the hero of the Bible, the man who brought God's word down to earth from the mountaintop. When we think of Moses, we think of his triumphs: leading the Israelites out of slavery, splitting the Red Sea, ascending Mount Sinai to receive the tablets of the law. But Moses was a man who knew frustration and failure in his public and personal life at least as often and as deeply as he knew fulfillment, and we, whose lives are also a mix of fulfillment and disappointment, can learn from his experiences. If he could overcome his monumental disappointments, we can learn to overcome ours.

What if, without aspiring to be another Moses, we could be like Moses in our ability to overcome disappointments, frustration, and the denial of our dreams? What if we could learn from Moses how to respond to disappointment with faith in ourselves

and in our future and to respond to heartbreak with wisdom instead of bitterness and depression? Can Moses teach us not how to be another Moses, but how to be ourselves, our best selves, even when life doesn't turn out as we hoped it would? The answer is Yes.

As a rabbi, I spent much of my time trying to comfort people for whom life had been harsh, men fired from jobs to which they had faithfully devoted themselves, women whose husbands had left them for no reason other than a flight from middle age, parents of a child killed by a drunk driver. Much of the time, I felt helpless, unable to think of anything to do or say that would heal them. And much of the time, they astonished me with their resilience. It was not that they didn't hurt. It was not that they denied the reality of what had happened to them. They understood that pain and rejection are part of life, and they responded to the shattering of their dreams by saying, I've learned how painful life can be and I want more of it because there is so much in life that is good and I don't want to miss out on it. They came to see the scars on their souls and sometimes the actual scars on their bodies, not as disfiguring, not as testifying to their being victims, but as battle scars earned in the struggle against the unfairness of life, a struggle in which they were determined to prevail.

Perhaps the enduring lesson of our failures is the one I learned from reading one of the great books of the twentieth century, Viktor Frankl's *Man's Search for Meaning*. Frankl was a prominent psychiatrist living in Vienna when Nazi Germany absorbed Austria in March 1938. Because he was a Jew, he was interned in Auschwitz but was fortunate enough to survive. Looking back on his Auschwitz experience, he wrote, "Everything can be taken from a man but the last of human freedoms, the right to choose one's attitude in any given set of circumstances." In other words, *what happens to you, no matter how hurtful or unfair, is ultimately less important than what you do about what happens to you.*

Robert Frost once wrote,

The tree the tempest with a crash of wood  
Throws down in front of us is not to bar  
Our passage to our journey's end for good  
But just to ask us who we think we are.

When life has dealt you a painful blow, let it hurt but trust yourself to get over it. Even as God blessed our physical bodies with recuperative powers, so that most of the time, most people recover from illness and injury, it would seem that God has



blessed our souls with the miracle of resilience, so that most people, most of the time, survive their pain, bear their scars nobly, and manage to go on living, surprising themselves and those around them in the process.

We were all deeply moved by the courage displayed by Christopher Reeve in the nine years following the accident that shattered his near-perfect life and left him paralyzed. We admired his refusal to sink into despair, his unyielding optimism, his commitment to arduous physical therapy. But the most remarkable thing about his story is not that he was able to do it. It is that you don't have to be Superman to do it. Millions of people have been crippled, assaulted, betrayed, or diagnosed with incurable ailments and have responded as courageously as Christopher Reeve did, insisting on going on with their lives and reaching for as much fulfillment and happiness as was available to them.

In June 2004, I officiated at the wedding of a woman who spends her waking hours in a wheelchair, having lost the use of her legs to a degenerative disease. It robbed her of her mobility, but not of her sense of humor, her courage, or her readiness to enter into married life. Shortly after that, I read the latest book by Stephen Hawking, the British physicist who can barely move or speak but nonetheless continues to revolutionize the world of physics with his insights. I have autographed books for people who attended my lectures but lacked the physical dexterity to shake my hand or the verbal facility to tell me their names or what was wrong with them. But they were able to hold down jobs and form emotional attachments to others. They are not living the life they had looked forward to when they were young, but they are finding happiness and meaning even in the difficult circumstances they find themselves in.

I continue to find proof of the reality of God in the ability of ordinary people to do extraordinary things, and I include not only the afflicted men, women, and children who show such remarkable courage, but the friends, families, doctors and nurses who respond to them with love and compassion where there might easily be neglect and resentment. Human beings at their best and bravest continue to amaze me.

I don't think I could have said to Christopher Reeve in the days after his accident "Don't let this one thing define you." What I might have said to him, what he apparently thought of by himself was, Concentrate on what you have left, not just on what you have lost.

I remember reading many years ago that one of the secrets of living a long and healthy life was to have been seriously ill when you were young. The person who has known sickness early in life

will be cured of the illusion of invulnerability, the myth that bad things happen only to other people. (Learning that our son had an incurable illness when he was three years old was that much harder for me to take because I had led a charmed life to that point.) Having known sickness and suffered from it, a person will learn to take care of himself to reduce the chance of it happening again. It may be equally true that the best way to immunize yourself against being crushed by failure and frustration is to experience it at an early age and learn that you can survive it. There is life after failure, and it can be a very satisfying life. Some people who fail early in life will learn to think of themselves as failures. But others will learn that a broken heart is like a broken bone – it hurts terribly but it heals, and, as has been suggested, it often heals stronger at the broken place.

A woman who wanted to tell me how helpful she found one of my books after her husband's death in an automobile accident wrote: "Admitting that I had no choice but to accept what had happened to me was not a statement of defeat ... I was giving up the illusion that the circumstances of my life were under my control, a cherished but dangerous notion I had held for a long time and which had at times laden me down with guilt when things didn't go right and I blamed myself." Instead of exhausting ourselves

"Dance as if no one were watching  
Love as if you'd never been hurt."

– *Judy Collins, The Rose*

trying to reshape the world to fit our dreams, we are better off using our strength to comfort one another in a world that is almost certain to mock our dreams and break our hearts.

In her book, *Scarred by Struggle, Transformed by Hope*, Sister Joan Chittister wrote: "There is no such thing as a life without struggle ... There is no one who does not have to choose sometime, some way between giving up and growing stronger. There is no one who has not known what it is to lose in the game of life. ... The essence of struggle is the decision to come out of struggle, out of suffering the same person they were when they went in. Some come out worse, soured on life. Others come out stronger and wiser." As the composer Leonard Cohen puts it, "There is a crack in everything; that's how the light gets in."

The most valuable, most enduring lesson we can learn from Moses comes not from his successes but from his failures. It is not about standing up to rulers and demanding justice. It is not about being charitable to the poor or respecting our neighbor's property. It is about facing our past with gratitude and our future with confidence, even as we carry with us the memories of dreams that never came true. There are other, more attainable dreams waiting for us.

# Enrolling as a Researcher to Obtain Tissue

VHL Family Alliance has formed a partnership with the National Disease Research Interchange (NDRI) to begin a new tissue bank. The tissue bank will store organs and tissues, including blood, urine and saliva.

NDRI is a non-profit organization funded by the National Institutes of Health with over 25 years of experience. NDRI offers the following:

- Nationwide access to human tissue from NDRI's established network of tissue retrieval sites.
- Expert review of researcher protocols for collection, preservation and delivery of human tissues and organs by NDRI.
- Computerized matching of researcher requests with available tissue.
- Retrieval kits for selected tissues designed for efficient collection that preserve quality and viability.
- Immediate access to NDRI's Online Biospecimen Catalog.

NDRI will register your protocol and work with you to collect tissue that meets your requirements. If you wish to prepare cell lines, for example, they can arrange quick transfer of fresh samples. Some reference cell lines are being prepared at the bank.

NDRI is available 24 hours a day at 800-222-6374. To be able to apply for VHL tissue, fill in an online application form at <http://www.ndriresource.org/html/applications.htm>. You will need to have the following:

- Electronic copy of your research synopsis
- Electronic copy of the resumé of the Principal Investigator
- Signed IRB letter of approval or exemption or equivalent (submitted via fax)
- Details regarding your tissue needs (i.e. donor and time constraints)
- Contact information for all co-investigators and individuals authorized to accept tissue in your laboratory
- Billing Contact and Payment Method.

If you are interested in cell lines please let us know as we are looking into making them available in the future.

If you have any questions please free to contact Joyce Graff ([director@vhl.org](mailto:director@vhl.org)). Specific queries about your research requirements can be directed to NDRI's Rare Disease Coordinator or John Lonsdale ([bank@vhl.org](mailto:bank@vhl.org)).

*Partners in Hope!*



## It's Easy for you! ... and it's Gold for us all.

Over the Thanksgiving holiday a VHL member was undergoing a procedure to drain a pancreatic cyst. I suggested donating the liquid that came out of the cyst. She replied, "Who wants it? It's only water." She really didn't want to be bothered and didn't have access to email or fax to sign a consent form. It was a holiday weekend, the pain was excruciating and she thought it was insignificant. I asked her: "If it's easy for you, will you do it?" I was told yes. Her interest was then relayed to the doctor by the patient. The doctor took some liquid for himself and put the rest in the fridge.

I called the NDRI, the National Disease Research Interchange, on Friday, the day after Thanksgiving, the same day the procedure was done. The NDRI called the VHL patient and received the consent over the phone, the name and number of the doctor, and had the fluid picked up.

Later I received a phone call from the patient. She was amazed. "What do they think it is, GOLD? They were so excited!" Yes, it is GOLD to them ... to us all.

For the advancement of VHL research, donate anything you no longer have use for. (If you can hang a lesion from a chain, that's another story!) But any tissue or fluid removed like this is precious for research. Help us ... and help yourself ... find answers. Even if you don't think it's VHL-related, donate it. Anything that comes from a VHL patient is GOLD! Let's recycle for all of us!

Just call 1-800-222-6374 and follow the prompts. If you need help or you can't handle everything because you are overwhelmed, call me. I would be happy to assist. I can be reached at 800-767-4845 extension 711.

Be well,  
Gale Lugo, Southeast Regional Chair  
800-767-4845 x711

For more information and forms, go to  
<http://www.vhl.org/bank>

***Thank you!***



## A Fast Horse

-- Renee S., Ontario, Canada

September 2006, posted in the online discussion:

Hello all. I wanted to write for a few reasons: to give you an update on my dear, sweet son Noah (eight years old), to thank those of you who replied to my emails about Noah and showed your concern, and offered prayers (thank you ... that support did help me through a very low point), to share a great story with you, and to ask for a favour.

I did get Noah's 24-hour urine results and they were not good ... double the normal adult value for noradrenaline and metanephrines. I have been in contact with NIH (the U.S. National Institutes of Health). Noah had pheo surgery there in November 2004 and then again in May 2006 -- the latter to remove two pheos. They asked me to keep track of his blood pressure for a few weeks, two or three times per day, and fax them the results. The numbers seem to be on an uneven upward climb.

Of course something is going on. Either an additional tumour was not identified in May (despite a harrowing number of scans) or one of the tumours they thought they removed managed to leave some part of itself behind. Or a new tumour sprouted within days of that last surgery. Anyway, my son has a pheo. This is some kind of torture for our family. I can't even think of a word to describe how I feel.

Anyway, I heard a great story last week and I want to share it (bear with me on length here).

A Canadian children's book author, Richard Scrimger, was writing a novel about a blind boy and he wanted to know what politically correct term to use, so he asked a boy named Ben (blind from birth) what to call it ... physically challenged? differently abled? Ben said no, he prefers to call himself 'handicapped.'

Richard was shocked ... he thought that was a derogatory term. So Ben asked Richard if he knew

anything about horse-racing. Not really. So Ben explained how horses who have won previous races are made to carry more weight, so they don't have as much of an advantage over the slower horses. This is called handicapping.

Then Ben asked Richard which horses are handicapped, the fast or the slow? The fast ones, of course. And Ben said, how could that be derogatory? I am a fast horse, so I have to carry a little more weight.

I love that story. Richard wrote the book (*Charlie's Point of View*) and it is dedicated to "fast horses who are carrying more weight."

That makes me feel good, and strong, and reminds me that I can get through this.

Now the favour: please keep Noah in your thoughts and prayers. This is a lot of weight to carry and it might help if some of you other fast horses share a small bit of the load.

December 2006, update:

Noah did have surgery again in November to remove his fourth pheo!!! It was done at the NIH, and they removed his entire right adrenal gland along with small pieces of both his liver and right kidney. They were concerned about cancer because of how aggressive the tumour was ... it grew very quickly. It was a bit of a tough recovery for a while there, but at last Noah is doing well. He developed a pulmonary embolism after surgery and he was on blood thinners for over a month, with the last injection on Christmas eve. The pathology came back clean! Hooray!

Noah has been through so much that a friend encouraged me to apply ... and the Canadian Children's Wish Foundation is granting his wish to visit Disney World with his family in February. Hopefully 2007 will be a much better year for us all!



Michael, Geoff, Renée, and Noah.



# Hats off to Audrey, Dawn and Lois

Three of our longest serving Chapter Chairs are looking to retire this year. Audrey C., Dawn C. and Lois E. have all volunteered for an amazing 12 years for the VHL Family Alliance and achieved some truly inspiring results. We would like to thank them for all they have done.

Audrey C. will be retiring as the Chapter Chair in North Carolina. Audrey was asked to be a Chapter Chair at one of the VHLFA annual meetings, and took on the role with gusto. Audrey has been championing against VHL for over 35 years and has been helping others to do the same.

Audrey is altruistic by nature, and her commitment to volunteering for VHLFA matches that of her volunteering for local hospices and the



Audrey (left) at the North Carolina meeting, 1998.

Outreach program of her local church. Audrey has arranged many statewide meetings and was awarded Chapter Chair of the Year in 1997 for her work in growing the Chapter;

"She has done an outstanding job of communicating with the medical community and general public in her state via newspaper and radio, as well as directly with physicians and hospitals."

Audrey has also enjoyed educating and helping people in her role as a hotline volunteer. She is looking forward to working with us in other ways. "I'm with you for life," she says. "After all, I have VHL for life."

Dawn C. will be retiring as the Chapter Chair in California. Dawn began volunteering for the VHL Family Alliance in 1994. Dawn was motivated to become a Chapter chair by her sister and neighbor, who both have VHL. Dawn has organized eight statewide meetings, one regional meeting and hosted the 2001 VHLFA National Meeting. An impressive



Dawn (left) leading Tai Chi at the Palo Alto Meeting (2001), the same year that she was honored as Chapter Chair of the Year.

record! Dawn utilized a number of hospitals in California, by basing her meetings at a different university medical hospital each time.

Dawn has brought compassion, spirit and Tai Chi to the California Chapter, cultivating special relationships and finding great reward in the

relationships she has built. Dawn comments on her time as a Chapter Chair;

"By and far, the best experience has been meeting people through the meetings and helping people over the phone and through e-mails. Several members have attended every (or nearly every) meeting we've had, adding warmth, knowledge, and well-received humor. Their names are Derrick R., Lynette R., Virginia L., and David L. I can't thank them enough, and I treasure their friendships."

Dawn has supported the members of her Chapter, through being a fountain of knowledge and providing help through phone, email and in person. Dawn helped us complete our initial registration with the State of California, allowing us to fundraise there.

Lois E. will be retiring as the Chapter Chair in Minnesota. Lois was one of the first people to contact us, in response to an article citing Joyce Graff's work with VHL that appeared in *Reader's Digest* in 1992.

Lois has VHL herself, and has been a great advocate for educating doctors and lay people alike to improve diagnosis and treatment of VHL. Lois shared her knowledge and personal story in order to help others, and chaired the first ever VHL meeting in Kansas City in 1994.

Lois comments on her first statewide meeting;

"We had our first Minnesota VHL meeting August 23 1993. There were thirteen people present, and a number who were unable to attend. There were quite a few new members hungry for information and excited about the Alliance, as we were in 1993 -- we had no handbook, we knew very little."

Since then Lois has organized a statewide meeting every year and did a fantastic job of providing the much needed information, and of growing the membership in the Chapter. Lois also answered many calls as a volunteer on the VHLFA hotline.

New leaders are arising in these and other chapters around the country. Won't you help to grow services and awareness in your own community? Call the office, or contact the current leaders in your region to volunteer your help.

Call toll-free 1-800-767-4VHL extension 4, or +1-617-277-5667. Thank you!



Lois (left) with genetic counselor Vicki Couch from the Mayo Clinic at the 2000 VHL Symposium in Rochester, Minnesota, which Lois, Vicki, and Kelly Heselton organized.

# Dancing for VHL

by Cari E., Ohio

I've been ballroom dancing for seven months, and taking private lessons with a professional dance instructor. It has been such a wonderful, positive experience in helping me to cope with having VHL disease! I'm training to be a student dance performer at upcoming Ballroom events with my teacher.

This whole experience has helped me tremendously cope with VHL. I finally feel there is more to my life than just having a disease.

I've attached a picture of me with my dance instructor, Timothy Nyman of Black Tie Dance Studio.

In Fall 2007 Black Tie and Tom Cruise Limo Service will be working together to have a Black Tie Gala Extravaganza to raise money for Multiple Sclerosis (MS) and VHL disease.

Their 2006 event partnered with the Cleveland Clinic to raise \$5000 for MS. Next year, Tom Cruise and I will be working together to raise money for MS and VHL by having another Black Tie Gala Extravaganza.

Black Tie Dance Studio -- including me! -- will be performing for entertainment.

This is our goal for next year!



Cari with Timothy Nyman, Black Tie Dance Studio, 2006

## Give for a cure!

**Support VHLFA through your  
workplace giving campaign!  
CFC, United Way, and others**



*Joyce not only put her money where her mouth is ... she also put her kidney!* -- Bruce S. Weinberg, J.D. [Photo Areti]

## Joyce's Leadership Displayed

-- Alex Lewis

The Genetic Alliance held its 20th Anniversary Gala in September, a celebration of 20 years of education and advocacy for organizations committed to rare genetic disorders. Joyce Graff was honored as part of a leadership exhibit, celebrating the exemplary leadership of those who have made organizations like ours possible.

"Joyce Graff, VHL Family Alliance. A founding member and indispensable part of the VHL Family Alliance, she embodies the ideal of leadership and dedication. As founder, member, volunteer, and now staff, she has donated her time, energy, and organ to bring together patients, physicians, and researchers to find, treat, and cure von Hippel-Lindau disease."

The quote and caption were written by our very own Bruce Weinberg, Chairman of the Board of Directors. He refers to how Joyce has given everything for the cause of VHL, including her gift of a kidney to her son Damon.

All the Board, Staff, and volunteers appreciate her ongoing leadership. Thank you, Joyce!



**Find friends, learn about new treatments, find clinical trials ...  
Join the online discussion group at  
[vhl.clinicahealth.com](http://vhl.clinicahealth.com) ... See p. 10**

## Mercy Medical Airlift

As more clinical trials become available to people with VHL, more people may be looking for ways to economize on travel to seek treatment -- at NIH or at any other center offering trials for one of the new drugs coming up.

Mercy Airlift will arrange deeply discounted or free tickets on commercial flights to help people in this situation.

Mercy Airlift is part of a consortium of charitable flight alternatives that includes empty seats on private corporate jets, and short-haul ambulance-style transport for those who need it, but for this purpose a seat on a regular commercial flight will usually do just fine.

Contact the Patient Assistance office at 757-318-9174 or 1-888-675-1405. Ask to speak with Elaine or Jean. Say that you have VHL, which is a cancer syndrome. They arrange charitable seats on commercial flights for cancer treatment.

On the web at <http://www.mercymedical.org>

## Hospital Hospitality Houses

When we travel far for treatment, hotel costs can add significantly to the financial burden.

The National Association of Hospital Hospitality Houses, Inc. is a non-profit corporation serving facilities that provide lodging and other supportive services to patients and their families when confronted with medical emergencies. Each facility assures that a homelike environment is provided to persons who must travel to be with a patient or to receive necessary outpatient care.

Contact them at Office: 828-253-1188, or Toll-Free: 1-800-542-9730, or by filling out the "Contact Us" form at <http://www.nahhh.org>

## Clinical Trial

*at M.D. Anderson, Houston*

Dr. Eric Jonasch of the Urology Department at M.D. Anderson Cancer Center in Houston is recruiting patients for his clinical trial of Sutent (Pfizer) for VHL.

This is an important study, because it tests the effectiveness of Sunitinib (otherwise known as Sutent), which has been approved by the FDA for use with advanced kidney cancer. It has not yet been approved "for VHL", so at this point most insurance companies will decline to cover the drug, believing it is "experimental". We have pretty good safety information about the drug because of the hundreds of people who took it in earlier trials for other conditions. What we lack is data on its effectiveness with the various kinds of tumors of VHL.

The goal of this trial is to find ways of controlling VHL with less surgical intervention. Specifically, it aims to determine whether Sutent is helpful in controlling VHL tumors. If so, the data gathered will help to get "VHL" on the label and make it more available for treating people with VHL.

Please read and discuss this information at [vhl.org/trials](http://vhl.org/trials). Patients and physicians are welcome to contact Dr. Jonasch or his clinical research nurse, Cherie Perez, at 713-563-1602.

## One-Stop Screening

A multi-centre study conducted by Sally Watts, a genetic counsellor at Guy's Hospital in London, England, has been published in "Familial Cancer" December 8th 2006 online. She studied the benefits to patients of consolidating their various screening appointments into one or two days, rather than spreading them out through the year.

Ms. Watts says, "I hope the results will now benefit screening for patients in the UK as our findings supported a one-stop screening service rather than ad hoc appointments. It also raises the need for psychological support which we have discussed at VHL meetings."

<http://dx.doi.org/10.1007/s10689-006-9111-y>

## Annual Meeting, 2007

Boston, Mass. June 23, 2007

John Hancock Conference Center, Copley Square, in the heart of Boston

see <http://www.vhl.org/meetings> for details

## New Online discussion

We have partnered with ClinicaHealth to create a new discussion forum at [vhl.clinicahealth.com](http://vhl.clinicahealth.com). Please come there and join the conversation!

This new, more modern format allow us not only to have interactive conversations on particular topics, but to organize the conversation so that newcomers can easily get up-to-speed, and so that we can find topics that have been discussed before.

There is also a place to create your own "blog" and tell us about yourself. You can upload a photo if you wish (or not if you prefer not to). If you want to post a photo but don't know how to do it, you can send a photo to the office and one of us will assist.

### ***We invite you to participate!***

Go to [vhl.clinicahealth.com](http://vhl.clinicahealth.com) to go directly to the VHL group. Follow the instructions to join the group. You will need to confirm your e-mail address by replying to an e-mail before you can log in and participate. You may want to print out a copy of the Quick Start Guide to help you in the beginning. It explains some of the key differences from the Yahoo group to ease transition for current members. You will find the Guide at [vhl.org/support](http://vhl.org/support).

One of our primary motivations in moving to ClinicaHealth is its very serious attention to security. Read the PrivacyPolicy to get all the details. Your address and personal details are not shared with anyone, not even with us.

ClinicaHealth will work with VHLFA to notify you of clinical trials that you might want to consider. Again, your information is not passed to researchers or pharmaceuticals, it is up to you to choose whether or not to contact them.

Please do not put your personal details into the messages themselves. The content of the messages can be seen by non-members as well as members. To make direct contact with another member of the group, send them an invitation to become a "friend". Once you have done this, and the other person has agreed to become your "friend," you can send direct messages to one another within the system, without knowing each other's e-mail addresses.

### ***Prefer another language?***

Choose a language: English German Spanish French Danish Swedish Norwegian Japanese

These are separate services where the entire discussion is in the language specified. French and Spanish are housed a YahooGroups.

- The French service is moderated by members of VHLFA, VHL France, and Alliance Familiale VHL du Canada, especially Guy Allegre and Gilles Brunet.
- The Spanish group is moderated by Jesusa



"Susi" Martinez, President, and Dr. Karina Villar of our Affiliate group in Spain, with help from Pierre Jacomet of Chile.

The German, Scandinavian, and Japanese services are similar, but use different technology:

- The German service is run by our VHL affiliate in Germany and Switzerland, moderated by Gerhard Alsmeier. You will find it at <http://www.hippel-lindau.de>
- The Scandinavian group is moderated by Vibeke and Richard Harbud. It has a choice of interface in Danish, Swedish, Norwegian, or English. You will find it at <http://www.vhl-danmark.dk>
- There is an "international" section in each of these Forums where English is the primary language.
- The Japanese group is moderated by M. Shinkai and Hanako Suzuki. You will find it at [http://www1.odn.ne.jp/vhl\\_japan](http://www1.odn.ne.jp/vhl_japan)

Follow the directions to register and join the conversation.

When you sign up for the discussion, they will send a message to your e-mail account to confirm that they have your e-mail address right. In order to complete your registration you have to respond to the message. It should arrive almost immediately - just go look for it when it tells you the message has been sent. This is to ensure that you are registering yourself, and that no one is signing you up without authorization from you. If you do not receive the message, it may have been stopped by your spam-catching software. Check in your "bulk" file or suspected spam.

### ***Now you're all set!***

In ClinicaHealth, go first to Messages and read the Welcome message. This will help you get started.

Every day you will receive an e-mail message, telling you what has changed. You choose what to read.

At the top of the page are the major sections. You will want to explore **Discussions** and **Blogs**.

Click **Surveys** to add your opinion to the polls.

We welcome your comments, both positive and negative. Please report all technical problems to Gale or to [webmaster@vhl.org](mailto:webmaster@vhl.org). We want you to be comfortable and successful in our interactive services!

Y'all come! [vhl.clinicahealth.com](http://vhl.clinicahealth.com) (Note no L)

# Influenza Vaccination for Caregivers

*From the U.S. Centers for Disease Control*

We know how important it is for at-risk groups -- children, people with asthma, people over 65, and people with any weakened condition (such as surgery) or immune suppression (transplants or treatment involving radiation). In other words, most people with VHL should get the flu shot.

What is less well known is that all members of the family of such people is equally important. Nurses, doctors, and caregivers are key to preventing the spread of influenza, a debilitating and highly contagious respiratory infection. It is caused by a virus and leads to an average of approximately 200,000 hospitalizations and 36,000 deaths in the U.S. each year.

An increasing number of people are going to work sick, trying to avoid taking time away from work, or not wanting to let the team down by being absent. But this means they are bringing their germs to work, and potentially infecting their colleagues, causing more total time away from the job. And if any of these workers is caring for a child, an elderly parent, or a family member who is sick, infections brought home to these vulnerable people could cause a serious or life-threatening situation.

The influenza vaccine remains the best way for caregivers to protect themselves, their families and the patients in their care during the annual influenza epidemic. Because the vaccine is altered nearly every year to match the circulating strain and because immunity from the vaccine wanes over time, the vaccine must be given each year -- ideally in October or November.

## Vaccine Myths Abound

**Q:** Does the vaccine cause the flu? -- No.

**Q:** Don't I already have immunity because I'm exposed to so many germs? -- No. Because influenza viruses are constantly changing, past exposure to influenza will not provide protection against newly emerged strains.

**Q:** Aren't the side effects worse than the flu itself? -- No, the most serious side effect occurs in people who are severely allergic to eggs (the vaccine viruses are grown in eggs). For this reason, people allergic to eggs are advised not to get the vaccine. The most common side effects are redness at the injection site and a sore arm. These symptoms are mild and go away in 1-2 days.

For more information about influenza and the influenza vaccine, visit [www.cdc.gov/flu](http://www.cdc.gov/flu) or call 800-CDC-INFO (800-232-4636).

<sup>[1]</sup> CDC, *MMWR*. 2004;52(RR06):1-40.

# How Can you Help? Search online!

***Each search earns pennies for VHL -- it adds up!***

Go to [www.goodsearch.com](http://www.goodsearch.com) and set as your preferred charity the VHL Family Alliance. Set this as your default search engine or home page using Tools / Internet Options / Homepage - Use Current.

## Shop online!

At iGive.com you can donate the commissions on your purchases to the Cancer Research Fund / VHL Alliance. *Give while you shop!*



## Recycle for VHL!

What did you get as gifts this season? Got a new cell phone? or iPod, or PDA?

Recycle the old ones, for benefit of VHL!

## Print your own pre-paid USPS mailing labels to recycle

Help raise money for VHL by recycling empty ink cartridges and old cell phones and laptops. With our new system it's easy, all you have to do is go to [vhl.org/help](http://vhl.org/help) then click on "Recycle" and print out the label. The value of the donated items will go directly to VHL.



Hang a poster in your workplace, or strategic locations around your neighborhood.

All makes of cell phones, iPods, PDAs, Palm Pilots and laptops are accepted. HP, Lexmark, Dell and Xerox ink cartridges can be accepted but NOT Canon or Epson.

Due to postal and customs regulations, this program only operates in the United States.



***Our Thanks for Donations from . . .***

***Thanks to all of you ...***

***We have met the December  
2006 challenges and more!***

***We will continue to raise money  
for the 2007 research grants***

***The Thank-you list appears only in the paper edition.***

***Donate a Car,  
Boat or truck  
see [vhl.org/help](http://vhl.org/help)***



***How Can You Help?***  
***Pick a Project - Help Raise***  
***Visibility***  
***Help Raise Money for a***  
***Cure!***  
***See [www.vhl.org/help](http://www.vhl.org/help)***  
***Set up your own personal***  
***fundraiser***  
***at [firstgiving.com/vhl](http://firstgiving.com/vhl)***

***The Thank-you list appears only in the paper edition.***

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*Executive Director, Editor VHLFF*  
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Gilles Bohlinger, +33 1 4893 3173  
*VHL France, france@vhl.org*  
Gerhard Alsmeier, +49-5931-929552  
*Chair, Verein für VHL Erkrankung b.F., Germany*  
M. Luisa Guerra, Italy, +39 (143) 643572  
*Chair, Alleanza VHL*  
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*Co-Chair, Canada, canada@vhl.org*  
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*Co-Chair, Japan*  
Erika Trutmann, info-ch@vhl-europa.org  
*Chair, Switzerland*  
Karina Villar, M.D., Spain, +34 937240358  
*Chair, Alianza Española de Familias de VHL*  
Mary Weetman, +44-(0)20-7681-1796  
*Chair, United Kingdom, uk@vhl.org*

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**VHL Family Forum, Newsletter of the VHL Family Alliance and the Cancer Research Fund / VHL**

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**E-mail: info@vhl.org; Tel: 1-617-277-5667; Fax: 1-858-712-8712**

**Toll-free in the United States and Canada: 1-800-767-4VHL**

**Editor: Joyce Wilcox Graff, 1-617-277-5667, extension 4**

**Internet website <http://www.vhl.org>**

**2001 Beacon St, Suite 208, Boston, Massachusetts 02135-7787 U.S.A**

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**United Way? write us in!****Look for us state or federal campaign brochures\***

**Please print out one or more posters from our website to hang in your office for workplace charity campaigns. Please note: \*We are not in all campaigns. If we are not listed in your workplace campaign, you cannot write us in. Please send a check.**

## Membership, Registration, Feedback

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Country: \_\_\_\_\_

Home phone: \_\_\_\_\_ Work phone: \_\_\_\_\_

E-mail: \_\_\_\_\_

**Preferences:**

**We can send you more timely information at a much lower cost via e-mail. We will continue to send a paper newsletter every three months.**

☐ I would like to receive our new monthly e-letter in 2007 ☐ Please send the paper copy as well

**Wristbands:**

**Wear your wristband proudly! Hope ... Strength ... Vhl.org**

Call the office at 800-767-4845 to make arrangements for bulk orders of wristbands.

☐ Please send me \_\_\_\_ # wristbands. I enclose my donation of at least \$5 for each. \$ \_\_\_\_\_



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

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: \_\_\_\_\_

\_\_\_\_\_

**Payment information:**

**Annual dues:** \$25 per mailing address (\$35 outside U.S.) ..... \$ \_\_\_\_\_

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

☐ My check is enclosed ☐ Please charge my Visa or Master Card: \$ \_\_\_\_\_

This is a ☐ one-time payment

☐ Monthly pledge to be charged to my card for \_\_\_\_ months.

Name as it appears on the card: \_\_\_\_\_

Card number: \_\_\_\_\_ Expiration: \_\_\_\_\_

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**2001 Beacon St, Suite 208, Boston, MA 02135-7787**

# Meetings Coming up -- Please Join Us!

## **Massachusetts - Boston Marathon Party!**

2001 Beacon Street, Suite 208  
Cleveland Circle, Brighton, Boston, Mass.  
Monday, April 16, 2007  
12-3 pm - view the race from our second-floor  
windows overlooking Beacon Street!

## **Massachusetts - Boston Annual Meeting and Conference Saturday, June 23, 2007**

John Hancock Hotel & Conference Center  
Copley Square, Boston

**An important meeting** for people interested  
in VHL issues of the eye, pancreas, kidneys.  
We will also be talking about progress in drug  
development relevant to VHL as well as kidney  
cancer in general.

## **8th International Medical Symposium on VHL, Copenhagen, Denmark September 4-6, 2008**

Conference center, Hotel Sct Petri, Copenhagen  
Chairman: Dr. Leif Wiklund, Sweden  
Organizing Committee Chair: Vibeke Harbud,  
VHL Denmark

## ***Become a part of the VHL Family Alliance Team!***

The VHL Family Alliance is looking for  
volunteers for the following positions:

- ***Awareness Advocates***
- ***Member Advisers***
- ***Regional Advisers***
- ***Fundraisers***

**Qualifications:** The desire to improve life  
for people affected by VHL.

**Hours:** As many as you would like to give!

**Compensation:** \$0, and the glow of  
knowing you are making a brighter and  
better future for people affected by VHL.

*If you are interested, or know someone  
perfect for the job, please contact  
director@vhl.org or phone the office on  
1-617-277-5667 extension 4.*

*We Would Love to have **You** on the Team!*



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