



*Family, Friends, Physicians, & Researchers dedicated to improving diagnosis, treatment, and quality of life for people affected by von Hippel-Lindau.*

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## Banking Tissue Spurs Research

In this issue we introduce our new initiative in Tissue Banking. With your help, we will encourage more researchers to study VHL, accelerate drug development, and exert more control over the process. The success of this effort depends on *You!*

More than ten years ago we formed a relationship with the University of Maryland to bank surgically removed tissue from people with VHL in order to assist researchers in finding tissue. More than 75 people with VHL have generously donated tissue to this collection.

Our goal in creating a bank was to encourage more researchers to undertake the study of VHL.

The availability of tissue often determines which disease a researcher will study. For example, if one wanted to study VHL aspects in the pancreas, it would be necessary to identify at least 20-30 people with VHL in the pancreas, wait for them to need surgery, and collect the tissue in one place. It might take years to identify enough people for a meaningful study.

"If a disease is rare, individual centers may not see enough patients to collect a critical mass of samples, and smaller drug companies often don't have the resources to find patients. Patient groups have also found that study results often are not shared with other researchers, and legal fights have broken out over who owns the rights to potential therapies developed from tissues." (Marcus, see Note 1.)

For these and other reasons, patient groups like ours are beginning to create tissue banks of their own.

The Bank at the University of Maryland has been helpful, but has not been as successful as we had hoped. We reviewed the results and interviewed researchers to determine what was lacking. For the study of von Hippel-Lindau disease, researchers have told us they need more than just tumor tissue. They need blood, urine, DNA, and tumor tissue as well.

We have spent nearly three years evaluating

options, and studying the evolution of tissue banking. The National Cancer Institute has recently announced new guidelines for the consistent storage and cataloguing of tissue so that samples from multiple institutions can be used together in a meaningful way. We were determined that our bank should follow these guidelines.

We are pleased to announce that we have chosen a new partner in Tissue Banking. We have joined the Rare Disease Initiative of the National Disease Research Interchange (NDRI) and the Office of Rare Diseases (ORD) of the U.S. National Institutes of Health. With NDRI as our tissue banking partner, we will be able to store the blood, urine, DNA, and tumor tissue required by today's research and drug development.

Rare diseases provide a particularly helpful view into cancer research.

"Scientists hope that by studying the DNA of patients in families where members across several generations get a particular cancer, they can home in on the genetic variations that make these families susceptible.

"This is critical because it turns out that the same genes are often involved when people in the general population get cancer. So the genes yield new insights into how cancer works, and for developing drugs. In just the past six months, for instance, the Food and Drug Administration approved two new kidney-cancer drugs that were developed in

*cont'd on page 2*

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Back to School -	near you!

**Please note our new address! See page 8.**

part using genetic information from cancer-prone families.” (Marcus) These drugs, Sutent (Pfizer) and Nexavar (Bayer and Onyz), are not yet the “magic bullets” that we are all hoping for, but they are significant advances in cancer treatment, and people with VHL have helped to develop and test them.

Amy Dockser Marcus, in several articles in the *Wall Street Journal*, provides examples of families prone to colon cancer, prostate cancer, and kidney cancer. The study of kidney cancer has been advanced through the study of von Hippel-Lindau disease.

In order to further the study of familial diseases, patients are often asked to enroll in registries. For the more common diseases (lung, colon, and breast cancer) there are registries at a large number of hospitals and centers. For the rare disease, however, except for some large centers, there are no large collections of tissue ready for study.

“It remains challenging to find families to participate in such research. Some people simply don’t want to come forward. Others are willing to participate, but the people affected by the disease have died and their DNA isn’t available for study. Researchers hope that through patient advocacy groups, media reports and word of mouth, they can reach more people.”

“One reason families with inherited cancers are so valuable to research is that they make it much easier to home in on the problematic genes. To find culprit genes in a vast population of patients with varying genetic makeups can be almost impossible. When the people getting the disease are all related, it is often easier for researchers to detect relevant genetic patterns.

“In families, there are more needles and less haystack to search for the cause of the cancer,” says Sanford Markowitz, an investigator at the Howard Hughes Medical Institute and professor at the Ireland Cancer Center and the Case Western Reserve University School of Medicine in Cleveland, who heads the familial-colon-cancer study.” (Marcus)

In kidney cancer, research into families led to the discovery of the so-called von Hippel-Lindau gene, which in turn was useful in the development of the new drugs, Sutent and Nexavar, for advanced kidney cancer. People born with one faulty copy of the gene have what is known as von Hippel-Lindau disease, which puts them at much higher risk for tumors, including kidney cancer.

W. Marston Linehan, chief of urologic surgery at the National Cancer Institute, whose group helped find the VHL gene, said that inherited kidney cancer is very rare, comprising only 4% to 5% of cases. But the same VHL gene is also involved in the majority of kidney cancers in the general population.

Alice Coday, 51, says her father, who had von Hippel-Lindau disease, died at the age of 53 from complications of it. Ms. Coday and her two siblings have the disease. All three of them are being followed as part of a family study at the National Institutes of Health.

Ms. Coday has had five surgeries related to the disease, including two to remove tumors in her kidneys. “Most people wonder if they’ll get cancer,” said Ms. Coday. “VHL families wonder when. But because of the research on families, the gene was identified. That’s always the first step leading to treatments.”

**References:** Many thanks to Amy Dockser Marcus and the *Wall Street Journal* for two insightful articles on this subject, dated May 23, 2006, and July 11, 2006. amy.marcus@wsj.com

### **What is NDRI?**

The National Disease Research Interchange (NDRI) is a non-profit organization whose primary purpose is to obtain, preserve, and distribute human cells, tissue, and organs to researchers and scientists. They are directly affiliated with the National Institutes of Health, who strongly supports the NDRI’s Rare Disease Initiative, a project that provides scientists with the materials they need to understand and treat rare diseases.

The VHL Family Alliance is proud to be working with NDRI toward not only a cure for VHL, but also for renal (kidney) and other cancers.

**To sign up for tissue donation, contact the Rare Disease Coordinator at +1 800 222 6374.**

Donors who live outside the United States may still register and contribute tissue. Please check first with your VHLFA country chairperson to see what tissue banks exist within your own country. A list of country chairs can be found at [vhl.org/support](http://vhl.org/support). If you prefer to donate to the VHL Tissue Bank at NDRI, please discuss with the Coordinator any regulations that may apply to your location.

**7th Biennial  
Medical Symposium  
on VHL  
London, Ontario, Canada,  
October 26-28, 2006  
details on page 6**

# Tissue Banking for a cure

by Alexandra Lewis

Help contribute to a brighter future with VHLFA's NEW tissue bank

VHLFA is very excited to launch our new tissue bank at the National Disease Research Interchange (NDRI). The tissue bank will store an expanded range of human biomaterials, including blood, urine and saliva to put VHL at the forefront of the latest research. Some researchers have already signed up to use the bank, and more are expected soon, so now we need your help with donating tissue to the bank.

As the VHL gene has become more prominent than ever before in cancer research, the necessity for biomaterials has increased. Researchers from the Renal SPORE at the Dana-Farber/ Harvard Cancer Center need VHL tissue for their research into kidney cancer. Blood and urine are also crucial for research into identifying biomarkers - chemicals found in the blood or urine which would indicate the level of tumor activity in the body without expensive scans. New drugs require tissue to test them on.

A larger collection of biomaterials and their related medical records is essential to prevent research into VHL and other cancers from being slowed. The new tissue bank is the vehicle to ensure that research to better understand, treat and find a cure for VHL takes place. NDRI is a non-profit with 25 years experience in obtaining, storing and distributing human cells, tissues and organs to researchers and scientists. NDRI receives funding from the National Institute of Health towards their Rare Disease Initiative of which we are now a member. This project seeks to provide researchers with the appropriate materials to gain insight into rare diseases.

Donating to the Tissue Bank need not be a hassle. Contributors can choose whatever type of donation they feel comfortable with. The first donation option is to give blood and urine samples, this can be done at any time, regardless of whether you have surgery planned or not. All you have to do is request a sign-up kit and fill in a consent form. Next, you need to get less than an ounce of blood drawn from your local doctor and then send your samples back to NDRI in a postage-paid envelope.

The second donation option is during surgery. Frank C. of Colorado, has donated tumor/tissue three times, from his spinal cord, pancreas and testicles. Frank, a retired supervisor from the Department of Corrections for Violent Juvenile Offenders, has had 13 surgeries in 62 months. Frank writes of his donation experiences;

"The process has been this simple for us. Initially,



Paula and Frank C.

we called to voice our interest in the tissue bank. Paperwork was sent to confirm our interest in participation, and to get the ball rolling with the tissue bank (fax or mail). My paperwork as the donor was at best a five minute process.

"From there, we have called to notify the tissue bank of upcoming surgeries. During the call, we provide contact telephone and fax numbers to the surgeon's office and surgery site hospital to the tissue bank. The telephone calls average the same five minutes for each surgery.

"Then, before going into surgery, we make sure the nurse and admitting staff are reminded a tissue donation from the surgery has been set up just as a courtesy (perhaps the left hand doesn't know what the right hand is doing. Give these guys some credit--a hospital is a busy facility). Each time the donation has been confirmed immediately, and off to surgery I go.

"I understand there may be some concern about taking more tissue than is necessary. That is not how this works--what your doctor plans to take from your body is all that is taken. Samples are shared of the specimen that is harvested--no additional tissue is taken or required.

"I cannot encourage other VHL patients enough to allow tissue donation--it may save lives of the generations ahead of us--and we can be part of that--how wonderful is that!"

There are two options for registering with the tissue bank to donate during surgery. You can either fill in a consent form in advance of having surgery scheduled, like Frank did, or once you have a date for surgery. As Frank did, you will need to send the form back to NDRI and give them details



*Diane M. Connecticut*

of upcoming surgeries. They will sort out the rest. Diane M. echoes Frank's experiences:

"My name is Diane, I am 30 years old I, live in Connecticut, and have been living with VHL in my life.

"On February 28<sup>th</sup> 2006 I had surgery on my cervical spine. I have lost count of how many surgeries I've had, but one thing I always remember to do is to donate my tumors/cysts to the tissue bank. It's so incredibly easy, all I had to do is complete a couple of forms and the rest was done by the doctors and the tissue bank. By donating these tumors and cysts, I am helping researchers in our pursuit to find a cure. I strongly urge everyone to do the same."

The final type of donation to consider is when a loved one passes away. If you or a family member feels strongly that this what you would like to do, then a consent form can be filled out at any time and sent back to NDRI. When the time comes your family will need to contact NDRI, who are very respectful towards the donor families' wishes regarding funeral arrangements. If a family member passes without signing a consent form but their family feels they would have wanted to be a donor, the family can sign the consent form.

All types of donation are at no cost to the donor, except the cost of the blood draw if you would like to donate blood. The process has been set-up to be as simple and sensitive to donor and donor families needs as possible. NDRI are available 24 hours a day to fulfill your requirements. Tissue that was donated to our previous Tissue Bank in Maryland will be moved to NDRI in due course.

We are enthusiastic that moving Tissue Banks to NDRI will lead to many new developments in VHL research and we really appreciate you taking the time to read this article and consider donating to the bank.

To sign up for tissue donation contact the Rare Disease Coordinator at the NDRI at 1-800-222-6374, or [bank@vhl.org](mailto:bank@vhl.org).

For other questions, contact the VHL Family Alliance hotline at 1-800-767-4845 or [alex@vhl.org](mailto:alex@vhl.org).

## 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 organs or 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)) or Alex Lewis ([alex@vhl.org](mailto:alex@vhl.org)). Specific queries about your research requirements can be directed to Kim Annecharico ([kannecharico@ndriresource.org](mailto:kannecharico@ndriresource.org)) or John Lonsdale ([jlonsdale@ndriresource.org](mailto:jlonsdale@ndriresource.org)).

## Two Alex's, One Dream

*Childhood entrepreneurs use Lemonade Stand to take a stand against VHL.*

by A. Lewis

Alex Anderson of Margate, New Jersey raised \$10,000 for the VHL Family Alliance on his Lemonade Stand. He was motivated and joined by other exceptional and inspirational children.

Alex, 10, is fighting cancer not only for himself but also in memory of Alexandra Scott, who passed away in 2004, age 8. At age 4 Alexandra opened a lemonade stand in her front yard with the goal of raising money to find a cure for all kids with cancer. Her story moved people all around the world to make donations. After she died the Alex's Lemonade Stand Foundation was established to continue her efforts.

On June 10, 2006, Alex joined with the family of Alexandra to host his own official Alex's Lemonade Stand; "Two Alex's, One Dream". Alex looks to Alexandra as his role model, commenting "we both do the same thing and she was so successful, I want to be that successful and help that many people." Alex is well on his way to achieving his vision, with this year's proceeds being donated through the Alex's Lemonade Stand Foundation to fund a VHL research project.

It wasn't only Alex's very own original lemonade recipe that lured people from all over Margate. The event was made even more magical with the accompanying heavy blues music of child prodigy Patrick Droney & Bleak City. Patrick, 14, was awarded the 2006 Robert Johnson Star Award for most promising blues musician. Patrick hasn't let stardom and playing with the likes of James Brown go to his head; instead he uses his talents to raise money for philanthropic endeavors.

Patrick has much in common with the two Alex's -- entrepreneurial talents, a passion for raising money for charity and a childhood disease, von Willebrand disease, a bleeding and clotting disorder. Perhaps the positive attitude of these three leading lights is summed up by Alex when he says of VHL "You've got one life to live; you may as well make it good no matter what situation you're in."

After a rocky road of misdiagnosis, Alex was diagnosed with VHL at age 4 and underwent a life-saving 14 hour brain surgery to remove a tumor. Since then he has had 11 tumors removed from his eyes. However, Alex's prognosis is good and with regular screenings he is able to lead a fairly normal life.

Aside from all his fundraising Alex enjoys playing X-Box, swimming, cycling and hanging out with his friends -- only after finishing his homework, though! Alex is looking forward to a trip to Lego



*Alex and his sister Amy at the beach, August 2006.*

Land this summer. He is especially interested in investing in a Death Star to add to his legendary Lego collection. Apparently the 2,500 piece Ark Fighter that he built alone in 5 hours just wasn't enough!

The mastermind behind the publicity for the Lemonade Stand shouldn't be forgotten though. Karen Anderson, Alex's mother, is the Chapter Chair for New Jersey and is full of good ideas. To publicize the event, fliers were put around schools in three districts. It was in the newspaper and on local radio. Karen also wrote letters to significant community figures at the City Hall. The result was that the Fire Chief got back to her and the fire station became the venue. All the hard work certainly paid off and Alex and Karen aim to raise over \$10,000 next year.

For more information about Alex Anderson, visit [vhl.org/AlexAnderson](http://vhl.org/AlexAnderson). To learn more about Alex's Lemonade Stand Foundation visit [www.alexlemonade.org](http://www.alexlemonade.org).



*Alex and his mother Karen were interviewed by NBC television. Banner says "Alex's Alex's Lemonade Stand -- fighting childhood cancer one cup at a time. Two Alex's, One Dream"*



## Join us in Ontario

*for the  
7th Biennial Medical Symposium on VHL  
London, Ontario, Canada  
October 26-28, 2006*

We have planned an exciting three days for you in Ontario! Please join us!

### **For Researchers**

Those engaged in biomedical research, or interested in hearing the state of research, will want to begin at 8 AM on Thursday morning with an exciting lineup of speakers, reporting on the status of their studies into the mechanisms of VHL in the cell.

### **For Clinicians**

Clinicians will especially want to be there for Friday and Saturday's lineup of talks on improvements in diagnostics and treatment of the various aspects of VHL. Continuing Medical Education credits are offered by the University of Western Ontario. Nursing credits can be arranged.

### **For Families**

Families will not want to miss Friday and Saturday in particular. You should know that the language of this meeting will be technical. When we hold meetings designed for families, we ask the doctors to constrain the language and remember that they are speaking to patients.

This meeting, however, is designed primarily for doctors and researchers, to allow them to collaborate, and share the state of their research. As families, we need them to do that! So we don't want to hold them back by asking them to remember that patients are in the room too. In this meeting, we are listening in on a technical meeting, and we want them to move the research forward.

You can still learn a great deal, and we encourage you to come. It would be a good idea to re-read your handbook before you come, and perhaps bring it along so you have that glossary handy. Feel free to ask one of us for explanations in the hallway as necessary.

Saturday meeting is particularly designed for patients and their families. The Friday and Saturday meetings will be talking about clinical issues -- the latest ways of diagnosing and treating particular

kinds of tumors.

The Thursday meeting will be highly technical, allowing the basic science researchers to collaborate, exchange ideas, and move the pace of research forward. You are always welcome, but please know that much of Thursday will be challenging even for physicians.

### **Want to be a leader?**

Those who are leaders for VHL -- or who might want to become a leader -- in any part of the world are invited to a Leadership Meeting Saturday, following the meeting. Leaders from states of the U.S., provinces of Canada, and from any other countries of the world, are invited. This is a great opportunity to meet your peers, or to explore the possibility of becoming a leader in your own area. The most important work we do is at the local level -- raising the visibility of VHL and helping people with VHL feel less alone. There is always work for new leaders!

### **Fun Stuff Too!!**

We are planning lots of fun stuff around the edges as well. There will be time to schmooz in the hallways or over breaks and meals, talk with the authors of the many posters, and chat with the presenters.

### **Travel**

Fly to London, Ontario, Canada, airport code YXU. Or drive from Detroit or Toronto.

London, Ontario, Canada, is half-way between Detroit, Michigan, and Toronto, Ontario, Canada. It takes about two hours to drive from either major city.

### **Housing**

The conference hotel is the Four Points Sheraton in London, Ontario. A block of rooms is being held for us at the conference rate. When you make your reservation, please specify that you will be attending the Canadian VHL Family Alliance meeting.

Conference speakers and attendees are responsible for making their own hotel arrangements. Reservations must be made by September 29, 2006, to obtain the conference rate. Please reserve early to be sure to secure a room.

Standard rooms are \$99, Executive King Suites are \$109 and Deluxe Tower Suites are \$124, all prices quoted are in Canadian dollars. As of August 2006, \$99 CAD = \$89 USD.

### **Register by paper or fax**

See <http://www.vhl.org/conf2006> for details about the meeting, and for information about meeting registration and travel arrangements. Call 800-767-4845, ext. 4, for assistance by phone.

To receive the latest info via e-mail, be sure to register for our online mailing list at [vhl.org](http://vhl.org)

*We look forward to seeing you there!*

*You're comin', eh?*

## **Invitation**

*On behalf of the Scientific and Organizing Committees*, we would like to cordially invite you to join us for

### ***the 7th International Symposium on VHL and Hereditary Kidney Cancer and Pheochromocytoma.***

We have invited speakers with international reputations in the field of VHL. We have support mechanisms to share with patients and their families. We have resources to help focus attention on this disease that robs so many of us of our health and our future. The faculty for this meeting includes many world experts in various aspects of VHL clinical care and the basic science of kidney cancer. We have planned interactive sessions to facilitate discussion and foster collaboration amongst researchers, clinicians and patients affected by these diseases.

This symposium is jointly sponsored by the University of Western Ontario, the Robarts Research Institute and the Canadian von Hippel-Lindau Family Alliance. It is an opportunity for researchers, clinicians and trainees to interact with those who provide care for those living with VHL. It is a two-way street of communication, knowledge and support.

Researchers, medical practitioners, patients and their families will gather at the Four Points Sheraton in London, Ontario, Canada, this coming October to hear about the progress being made on von Hippel-Lindau Disease, a genetic, incurable disease, either commonly misdiagnosed or missed completely in diagnosis. This conference will be about research, awareness, and hope.

The fact that this significant event will be held in London, Ontario, is timely, given recent media attention to the predicted rise in cancer statistics for this region. An increase of 28.5% is predicted by 2015, and not all of that increase can be attributed to earlier diagnosis. Environmental, genetic and lifestyle components factor in greatly. With von Hippel-Lindau, the genetic factor predominates.

Heightened awareness is required for effective treatment of VHL. Early diagnosis means much to someone diagnosed with the defect on the VHL gene. It can mean that people with the defect may make better informed choices. It can mean that blurred vision occurring in a teenager may be something other than eyestrain or an eye condition, and that more thorough investigation may lead to tumours or cysts being discovered elsewhere in the blood-supply-rich parts of the body (spine, kidneys, liver and eyes).

It can mean better quality of life for the duration, thanks to gentler, more effective treatment modalities offered sooner. It can mean that a family physician with heightened awareness of VHL may look more closely and diagnose this disease earlier, when

treatment plans can truly work better. Heightened awareness can also mean more research funding for more researchers, more resources for those living with VHL and for those who care for them. It can mean more hope for an eventual cure.

So please, join us for this very important conference and help us "untie the knot" to VHL. Please click here for more information, symposium poster and to register.

With sincere thanks from,  
Stephen Pautler, MD FRCSC  
- Chair, Organizing Committee  
Jane Green, PhD  
- Chair, Scientific Committee

## ***Highlights of the agenda***

### ***Thursday***

Mechanisms of VHL-dependent tumorigenesis  
HIF-dependent and independent tumour suppressor functions of VHL

### ***Friday***

Nature of VHL Disease and Advances in Treatment  
Protocols

Eye  
Central Nervous System  
Pheochromocytoma and Paraganglioma  
Kidney  
Reproductive Tract  
Pancreas  
Polycythemia

Consensus Meeting

### ***Saturday***

Living with VHL  
Managing VHL  
Leadership meeting

***Early Transplantation  
A new research project would like to hear about people who received a kidney transplant less than two years following loss of their kidneys. Please contact the VHL Hotline to share your experience.***

## ***Give for a cure!***

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

# Get free donations to VHLFA as you shop for your wedding . . .

by A. Lewis

Thanks to the generosity and savvy of our members, the *VHL Family Alliance* office has been made aware of different fundraising websites engaged couples can use to raise money for the *VHLFA*.

The best option seems to be *The I Do Foundation* ([www.idofoundation.org](http://www.idofoundation.org)). You need to register (for free) as a couple with the *I Do Foundation* at their website. Once you have done this you can choose the charity that you would like money to go to, by clicking on 'select charities'. *VHL Family Alliance* is not on their initial 'recommended' list of charities, but there is also an option to 'suggest a nonprofit'. If you suggest the *VHL Family Alliance* they have already approved us and they will accept it as your charity of choice. Once you've done this, you have different choices for how money can be raised for *VHLFA*:

1) You can buy the essentials you need for the wedding through the website and shops that are in their list of partner vendors will give a different percentage to your chosen charity. For example, if you choose to shop for rings at *icecom*, they will give 5% to your chosen charity. However, you must shop through the 'shopping' section of the *I Do Foundation* website for the donation to be made.

2) You can create wedding gift registries on the *I Do Foundation* website for their partner vendors. You can choose one or more stores, and again they will donate a percentage to your chosen charity. Partner vendors include *Macy's* and *Target* amongst others.

3) You can create a charity registry so that guests can visit the website and donate money, which will go to the *VHLFA*. This could be in addition to or instead of wedding gifts. This may be a good option if you want to donate to *VHLFA* but you also need gifts, as you can set a limit to the number of direct donations made by guests through the charity registry. Therefore, you will still receive plenty of items from your gift registry to help you begin your new life together.

You can also use many of the *I Do Foundation* programs internationally, which is helpful if you are not one of our U.S. members. For example, the *I Do Foundation* will ship favor cards abroad, you can use the charity registry and some of the shopping and gift registry vendors are international. The programs available to couples in countries outside the U.S. vary from country to country, so you may need to contact the *I Do Foundation* once you've registered to find out what your best options are.

Another website is [www.weddingchannel.com](http://www.weddingchannel.com). This website will allow you to donate money to *VHLFA* if guests give money instead of gifts. However, this website will not give a percentage to *VHLFA* as you shop or through gift registries as we are not one of their '100 recommended charities' and they will not add us to their list.

Your final option is to set up a *First Giving* web page for donations, which is a great option if you would like money to go to *VHLFA* instead of receiving gifts, but we know not many people can afford to do that!

Another bright idea one of our members is using at their wedding is to use the *VHLFA* wristbands as favors. We have also worked with couples to prepare favor cards announcing their own donation to *VHLFA* in celebration of their wedding.

Thanks to those of you who have made us aware of these ideas and for thinking of donating to *VHLFA* at such a special but hectic time.

*Congratulations! Celebrate generously!*

## Growing to Serve you Better!

We have grown so much in the last several years that we need more space!

We had grown to two full-time and three key part-time staff and volunteers in one and one-half rooms in Joyce's house on Clinton Road, with materials stored in two other rooms. Joyce sold the house this year, downsizing in her retirement from the corporate world. She has moved to an apartment, and VHL has moved to a real office building!

Our new office is located at Cleveland Circle in Boston, near Boston College and the Brookline Reservoir. It is easy to get to on the Trolley (C or D lines) and several bus lines. Several other non-profits are housed in the same building, giving us a peer group to interact with in the halls.

Our new quarters include space for us to create pleasant workspaces for our staff and volunteers. We invite you to visit us any time. Please consider working with us as a volunteer, helping to expand the reach of the *VHL Family Alliance* and its programs. Among other projects, we need to decorate our new walls!

VHL Family Alliance

2001 Beacon Street, Suite 208

Boston, MA 02135-7787

All e-mail, fax, and telephone addresses remain the same.

# Back to School – Get Sox for your Books!

It's back-to-school time, and time to cover those textbooks to keep them fresh and clean.

BookSox are stretchy fabric book covers with delightful designs. When you purchase them through the mail or web, you can designate VHLFA as your favorite charity, and they will donate one dollar for each book cover ordered. We are registered with them as Cancer Research Fund - VHL

Each of you can begin your own fund-raising efforts locally by requesting advertising materials from Book Sox, at no charge! There are large posters with tabs at the bottom where we will write our organization number (02445-100). The student, teacher, Rabbi, Priest etc., can take the tab for their reference when ordering.

There are also smaller handouts which can be requested with our number already printed on them. Karen A., New Jersey, ordered 1000 and arranged to distribute them in her school district, in the hope

that the child's mom or dad will use it when they purchase their book covers.

These flyers can be placed in supermarkets, at the gym or at your church or synagogue. Just ask permission, first. The opportunities are endless. Be creative!

To request flyers, call Carole Meisse at 1-800-930-2241 or write to [carolem at booksox.com](mailto:carolem@booksox.com). Give her our organization number "02445-100", the number of flyers you need, and the address to mail them directly to you.

BookSox can also be ordered online at [www.booksox.com](http://www.booksox.com). To select us, enter "VHL" and choose the Cancer Research Fund – VHL.

**Have questions?** Call Karen Anderson, 1-800-767-4845, extension 719



## Click and Ship for VHL Print your own pre-paid USPS mailing labels to recycle

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# Opening Doors for Disabled Travelers

In May 2006 the Open Doors Organization (ODO) of Chicago hosted its first Airline Symposium, bringing together 33 airline representatives from around the U.S. to Chicago to discuss two important issues to travelers with disabilities -- safe stowage of scooters and wheelchairs, and maintaining high standards among contract workers who assist passengers with disabilities get to the gate and board the aircraft. Thirteen airlines participated in the 2-day event co-sponsored by the Air Transport Association. ODO staff shared the results and solutions from four years of research on these issues, as airline representatives contributed best practices to the group.

Cars, hotels, airplanes -- all the modes of travel present some special issues for travelers with disabilities. Smaller airplanes that use staircases are clearly a problem, but even with jetways and the ability to roll a wheelchair down the aisle, there may still be problems. The aisles are narrow, usually requiring transfer from the individual's normal wheelchair to a narrower "aisle chair" or "straight back chair". Airport staff are rarely adequately trained to lift and accommodate someone who cannot lift their arms or assist in the transfer.

Accessibility for disabled passengers is mandated by the Air Carrier Access Act, which was passed in 1986. The Americans with Disabilities Act, which bars discrimination against the disabled, was passed in 1990. Nonetheless, businesses "may be following the letter of the regulations in accessibility, but not the spirit of them. All too often companies fall short in the way they accommodate people." (Welch)

Hotels offer a small number of rooms outfitted for handicapped guests, but staff training is generally lacking. Travelers want to feel comfortable and welcome.

"There is major customer service inconsistency," said Eric Lipp, executive director of the Open Doors Organization, a nonprofit group based in Chicago that researches travel by people with disabilities. According to an Open Doors survey from 2005, more than 80 percent of adults with disabilities who have traveled by air encountered obstacles. Their two most common complaints were the handling of devices like wheelchairs or scooters and the quality of the contracted workers.

Mr. Lipp is optimistic the situation will improve. The Symposium was an important step. "The fact that 13 airlines showed up is amazing," he said. "They're really starting to open their eyes."

The airlines trade group helped organize the meeting. "We're always looking for ways to help our members improve their delivery of services and

ensure that they comply with the law," said Sophy Chen, a senior attorney at the trade association, who attended. The Open Doors survey showed that 71 percent of disabled adults -- more than 21 million people -- traveled in the last two years. And a 2002 study revealed that disabled people spent \$13.6 billion annually on travel.

"This is a huge market," says Lipp. Census Bureau figures released in April showed that 51.2 million people, or 18 percent of the population, had some sort of disability.

In addition, there is an increasingly large population of senior citizens. "There are a lot of mature travelers who don't self-identify as disabled but could use a walker or a large-print menu," he said. "They won't necessarily ask for it ahead of time, but if it's offered to them, they'll take it." Open Doors estimates that disabled and mature travelers spend \$38 billion on travel.

"This segment of the population has been overlooked," said Suzanne D. Cook, senior vice president of research at the Travel Industry Association of America. "Given that aging and disability are correlated, there will be millions more of these travelers." (Welch)

Level Travel, an organization in Coatesville, Pennsylvania, has a Web site ([www.leveltravel.com](http://www.leveltravel.com)) that ranks hotels and restaurants in major cities on their accessibility for four groups: older travelers and travelers with mobility, hearing or vision impairment.

Jamie Sharples, Level Travel's president, said he founded the company three years ago because of inconsistencies he found in the travel industry. "We wanted to provide a standard instead of getting someone's opinion" on whether a facility was accessible, he said.

In June 2006, Avis Rent A Car has announced a new pilot program with Scootaround Inc. that will give customers the ability to rent a mobility scooter and have it waiting in the trunk of their next rental vehicle or delivered to the customer's location. The program rolls out at two of the nation's most frequented leisure and convention destinations -- Las Vegas and Orlando. Avis is the first rental car company to offer mobility scooters combined with vehicle rentals. Visit [www.scootaround.com/news](http://www.scootaround.com/news) for more information.

Taxis for All is an organization that is making transportation more convenient for people with disabilities. Check out their website for more information <http://www.unitedspinal.org/advocacy/taxisforall>

**References;** See also Sara J. Welch, "Itineraries: Not so Accessible," the New York Times, June 13, 2006.



*Eric Lipp, Chicago  
Executive Director, The  
Open Doors Organization,  
and a member of the  
Board of VHLFA*

## Ask the Experts:

### **Partial Adrenalectomy**

**Question:** "I was recently told that I would probably not be able to have a partial adrenalectomy for my pheo - even though it's very small. The doctor said that the entire adrenal is overproducing and a partial adrenalectomy would only result in future pheos on the same side." -- *Angela S., Florida*

**Answer:** We used to hear this in the early 90's... when we first started doing partial adrenalectomies.

Our rationale is that we believe strongly in organ sparing management in VHL patients, whenever possible. When it comes to the adrenal, our goal in developing the minimally invasive, adrenal sparing partial adrenalectomies is because pheochromocytoma in VHL patients can be bilateral. We always work to preserve the adrenals in these individuals, whenever possible. We do not like to see both adrenals removed from a VHL patient (or any patient) whenever possible.

We know it is true that a pheochromocytoma can recur. However, in most instances, we feel that it is better to leave the functioning adrenal tissue. These patients are watched closely in any event, as pheos can occur even without adrenals. So, if a pheochromocytoma does re-occur (on either side), it can be managed (most often by minimally invasive laparoscopic removal).

At the NCI we rarely remove an entire adrenal gland in a VHL patient. When we do, the tumor is very, very large.

-- *W. Marston Linehan, M.D., Chief, Urologic Oncology Branch, U.S. National Cancer Institute, Bethesda, Maryland*

Diner, E.K., Franks, M.E., Behari, A., Linehan, W.M. and Walther, M.M. Partial adrenalectomy: the National Cancer Institute experience, *Urol.*, 66: 19-23, 2005.

### **GoodSearch for VHL!**

Set Goodsearch.com as your search engine of choice, and each time you search on the internet they will make a small contribution to VHL! It adds up!

## UK Annual Meeting

Our UK affiliate, the VHL Contact Group (VHLCG), held their annual meeting in April in Manchester, England, chaired by Mary Weetman. A full report of the meeting can be found on their website, [www.vhlcg.co.uk](http://www.vhlcg.co.uk)

*Peter Richardson* opened the day giving some insight into his life as a neurosurgeon and the issues he faces in his work. He delicately managed to discuss some of the factors around those critical operations, with which many in the group will be familiar, in an entertaining, light hearted and informative way.

Dr. Richardson talked about the "balance of decisions" he deals with every day, evaluating when to operate and balancing 'benefits versus risk'. The aim of surgery he saw as to control the disease, not to cure it. He described his job as 'plumbing' - although, as members saw it, of a very skilled nature.

*Eamonn Maher*, spoke about the state of genetic research on VHL. Since the finding of the VHL gene in 1993, the genetic implications and the understanding of VHL has accelerated. Identification of the gene has led to diagnostic testing, facilitating earlier screening and treatment, and thus an enhanced prognosis. Pre-natal screening is also an option. Progress has been made toward drug treatment, hoping to slow the development and growth of VHL tumors.

The moving and inspiring contribution given by *Dora and Andy Beeforth* is also on the website under 'Articles.

*Gillian Crawford* presented the outcome of her qualitative survey into how the diagnosis of VHL has affected patients' lives. It touched on the psychological impact of clinical monitoring and was welcomed by patients as an insight into how the diagnosis had affected their lives.

For her study Gillian Crawford had identified fourteen people of whom ten had responded. The material came from structured interviews, which were taped and transcribed. These revealed how 'not knowing' is a worry and the extent to which a diagnosis brings a 'certainty' and gives the condition a 'legitimacy'.

All the participants were actively employed. The diagnosis though raised other 'uncertainties' about the future in this context. It brought about a change in the view of an employer - 'my illness defines me in the eyes of others'. It becomes a threat to my self-esteem. No financial issues were raised.

The four participants who had children were having to consider the issue of sharing their knowledge with their offspring.

This research will be reported in more detail at the Symposium in October.

# Salt Lake Meeting

In Salt Lake we conducted the Annual Meeting, and heard from some very good speakers.

## **Vital Friends**

Tom Rath shared with us his own experiences with VHL, and the research he has conducted at the Gallup Organization on how attitude contributes to organizational health as well as family and individual health. His new book, *Vital Friends: The People You Can't Afford to Live Without*, is available August 1, 2006. *Vital Friends* helps readers identify the friendships that make their work and home life more positive and productive.

## **Insurance**

Tom Rodenberg spoke with us about insurance and negotiating successfully when your insurance company denies a claim.

## **Endolymphatic Sac Tumors.**

Dr. Russell Lonser of the Surgical Branch of the U.S. National Institute for Neurological Disorders and Stroke (NINDS), one of the National Institutes of Health (NIH) was our primary featured speaker. He updated us on their work on brain and spinal tumors of VHL, and especially shared with us his latest research on endolymphatic sac tumors (ELSTs). Since 1997, he and his group have been studying the natural history of ELSTs. They bring in a group of people with VHL for thorough checkups every 6-12 months, watching the progress of their symptoms and the growth of the tumor on imaging, and deciding when is the optimal moment to operate to get the best outcome.

They have learned a great deal about what causes symptoms to develop in this tiny structure. In 1997 we thought that the symptoms were related to the size of the tumor and the duration of symptoms. But that is proving not to be the case. Even very small tumors that cannot be seen on imaging can cause significant symptoms and hearing loss.

The sudden loss of hearing experienced by a number of people with VHL may be caused by a hemorrhage in the labyrinth, the coiled passages of the inner ear. Left untreated, this hemorrhage causes inflammation and eventual deterioration. Anyone with VHL who experiences a sudden drop in hearing should seek treatment immediately. Even after a hemorrhage, if the inflammation can be controlled there is some hope of regaining the hearing, but the time window of opportunity is short.

Lonser's team have now operated on 16 patients. In all cases, hearing was preserved at the same level as before the operation, but with no improvement. They recommend surgery for people with an ELST visible on imaging, especially who can still hear, to preserve the hearing. Even if the hearing is gone, if there are

increasing balance symptoms or other neurological issues, surgery may help to prevent a worsening of these symptoms.

Surgery may also be indicated if no tumor is seen on the images, but there is evidence of blood in the labyrinth and there are symptoms (hearing loss, tinnitus, and/or vertigo).

The technique they use is an incision behind the ear called a retrolabyrinthine posterior petrosectomy (RLPP). It is a smaller incision than most craniotomies, and does not require moving much muscle out of the way, so the recovery is easier. Some people had balance issues for a time after surgery, but these usually went away.

Kim, Butman, Glenn, Oldfield, Lonser, et al., Tumors of the endolymphatic sac in patients with von Hippel-Lindau disease: implications for their natural history, diagnosis, and treatment. *J Neurosurg.* 2005 Mar;102(3):503-12.

## **Survey on Dealing with VHL**

Melissa Savage recently graduated with a Master's degree in Genetic Counseling from Arcadia University in Pennsylvania. She wrote her master's thesis on "Discovering Self-Efficacy in Patients with von Hippel-Lindau disease," or in other words how medical professionals can evaluate the patient's ability to cope. The term "self-efficacy" is defined as "a broad and stable sense of personal competence to deal effectively with a variety of stressful situations."

Melissa composed a survey, obtained permission from the Internal Review Board at Arcadia and from the VHLFA, and posted an invitation in the online discussion to complete her survey on the internet. A total of 59 people responded, providing her with the raw data used in her paper.

Over all the general self-efficacy of the participants was slightly higher than expected. This group of respondents was already participating in an online support group, and was well informed about VHL, both of which are factors that help patients cope with their illness. Many people cited the importance to them of understanding how VHL works, how to screen for issues, and obtaining information on new treatments.

She concludes that it is not only important to treat each patient as an individual, but it is also important to inquire about their feelings and emotions. She hopes that the emotional side of VHL will get more attention both when doing research about VHL and when seeing patients with VHL.

Melissa would like to thank all those who participated in her study, and we would like to congratulate her on completing her degree.

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# Meetings Coming up -- Please Join Us!

## **London, Ontario, Canada** **7th Biennial Medical Symposium on VHL** **October 26-28, 2006**

See pages 6-7 for details

## **California**

Annual meeting this fall

Call or check [vhl.org/meetings](http://vhl.org/meetings) for details

## **Massachusetts - Boston** **Open House at our New Office!**

2001 Beacon Street, Suite 208

Cleveland Circle, Brighton, Boston, Mass.

Saturday, October 7, 10-2

Light lunch provided

## **South Carolina - Greenwood** **Saturday, November 18, 2006**

Chairman: Skipper Rice

Call or check [vhl.org/meetings](http://vhl.org/meetings) for details

## **Texas - Houston** **September 30, 2006**

Chairman, Dr. Eric Jonasch

This is the formal announcement of the Sutent trial for VHL at M.D. Anderson Cancer Center in Houston.

Call or check [vhl.org/meetings](http://vhl.org/meetings) for details

## **Germany - Mainz** **Mainz, Germany, October 20-22, 2006**

-- Gerhard Alsmeier, Germany

We will hold our annual meeting October 20-22 in Mainz. The language of this meeting is German.

Friday afternoon we have the opportunity to visit Bioscientia Institute. They will show us how DNA testing is carried out.

Saturday morning we will start with our membership meeting. After Lunch we will have presentations. Presenters include:

Dr. Decker, from Bioscientia Institute, will speak about DNA testing.

Dr. Hüwel, from University Hospital of Mainz, informs about diagnosis and treatment of hemangioblastomas.

Dr. Link, from Aeskulap Hospital Wiesbaden, will speak about pancreatic involvement.

In the evenings we will have the opportunity to share our experiences.

Sunday morning we will visit the more than 2000-year-old town of Mainz.

## **England - Manchester** **Nowgen Centre, Manchester, England**

Saturday 14 April 2007

Chairman, Mary Weetman

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