



## Welcome to our new Executive Director



*Ilene Sussman, PhD*

The Board of Directors is pleased to announce that Ilene Sussman, Ph.D. has been appointed as the new Executive Director for the VHL Family Alliance. Her appointment will become effective September 6.

Sussman joins the VHL Family Alliance after serving as the Executive Director of the North

American Thrombosis Forum (NATF) in Boston.

In Ilene's role at NATF she was responsible for expanding awareness, leading advocacy efforts on Capitol Hill, and expanding educational programs. In addition to managing the day-to-day operations, Ilene is credited with growing NATF, developing collaborative relationships, and presenting at national and international meetings.

Prior to her tenure at NATF, Ilene spent seven years working for the Boston Jewish community including positions at Combined Jewish Philanthropies and as the Founding Executive Director of DAF: Jewish Day School Advocacy Forum.

In addition to her decade-long tenure in the not-for-profit sector, Ilene utilized her biochemistry background in the pharmaceutical industry at Genzyme Corporation and Oravax as well as at Boston University Medical Center where she served as Research Assistant Professor of Medicine.

"As Joyce Graff transitions to her new role as Wellness Director, Ilene's skills and experience will be valuable to the VHL Family Alliance," said Jeanne McCoy, Board Chair. "We will look to Ilene to provide leadership and strategic direction as we aim to grow the organization, gain greater visibility, and increase our grant funding stream."

"I am delighted to welcome Ilene as our new Executive Director" said Joyce Graff who co-founded the organization in 1993 and is nearing retirement. "I look forward to working with her in my exciting new role as Wellness Director. With her strong leadership at the helm, I will be able to focus on improving our VHL Handbook and other publications, and working with the medical experts to strengthen the information available to doctors and patients throughout the country and the world."

Sussman earned her Ph.D. in Biochemistry from The Weizmann Institute of Science in Israel along with a MS, Biochemistry and a BA, Biology from the University of Pennsylvania.

## Pheo Survey

*By Joyce Graff and Sue Buckley*

In the summer of 2011 we conducted an online and telephone survey of 367 people with pheochromocytoma and/or paraganglioma. For the sake of simplicity, we will refer to both in this paper as "pheos". Most of the respondents were people who had contacted one of three organizations, seeking help with their symptoms. When they first reached out, many did not know what was causing their symptoms, but they recognized from the websites and discussions that their symptoms were not unique. Figure 1 shows the DNA diagnosis known when people first reported symptoms, and the DNA diagnosis now known.

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# Please also welcome our new board members



Jane McMahon Romanoff

Jane McMahon is an Executive Search Consultant with Opus Search Partners, a boutique executive search firm servicing clients in the healthcare, higher education and not-for-profit sectors. With over 10 years of executive search experience, Jane has completed senior-level assignments for a number of well-known and regarded institutions including Boston University, Dana-Farber/Harvard Cancer Center, Harvard University, Columbia University, New York University, and The University of Chicago, among others.

With a strong commitment to mission-driven organizations coupled with a desire to “give back,” Jane’s desire is to see the VHL Family Alliance gain greater visibility through research and educational grants and sees her involvement with the Board as a platform to increase public awareness, funding, and community involvement.

A native of Philadelphia, Jane earned her bachelor’s degree from Temple University.



Sarah Nielson

Sarah Nielson is a Genetic Counselor in the Cancer Risk Program at the University of Chicago where she educates and counsels those with a personal and/or family history of cancer. Sarah received a Bachelor of Arts in Biology from Lehigh University and a Master of Science in Genetic Counseling from the University of Pittsburgh. During graduate school in Pittsburgh, she worked as a clinical researcher for the Department of Endocrine Surgery, where her focus was on VHL type 2A. She had the opportunity to study two very large historic Western Pennsylvania families with VHL type 2A, and her extensive conversations with these families further sparked her interest in VHL from a scientific perspective as well as patient advocate perspective. Her findings regarding genotype-phenotype correlations in these two VHL families were recently published in the *American Journal of Medical Genetics and Familial Cancer*. Sarah is currently working to establish an Endocrine Genetics Clinic at the University of Chicago where VHL families can come for comprehensive care and support.

Sarah will use her background as a genetic counselor and VHL researcher to further reach out to and educate medical professionals about the disease. She will serve as a liaison between the public sector and the medical field and use her involvement with the Board to spread the word about the great services and research opportunities that the VHL Family Alliance has to offer. Sarah plans to continue her own VHL research and to translate the latest scientific discoveries into language that patients can easily understand.

As a native “Mainah,” Sarah is adjusting to her new life in the Midwest and its exchange of oceans for lakes and mountains for cornfields.

## VHL Victor

By Wheatley Davis, from the Facebook page: *VHL: Spreading Awareness of von Hippel-Lindau*

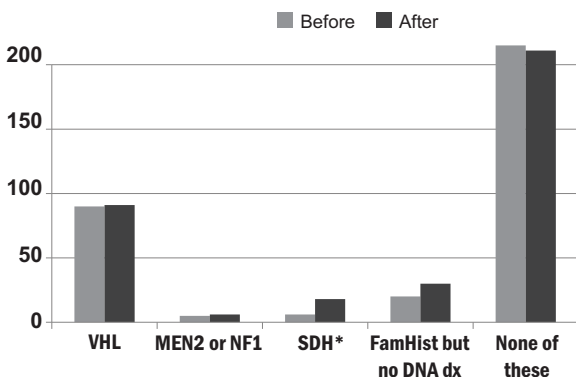
“VHL Victor” is just a phrase I coined by accident. Often we hear about “Survivors” – Breast Cancer Survivor, Survivors of 9/11, etc. Well, when I put up this post a month ago just to introduce myself to the group, I didn’t want to say “I’m a VHL Survivor”. While it is true that we all have “survived” through the turmoil that VHL may bring to ourselves and/or our loved ones, I prefer to

think of us as VICTORS, as in we are VICTORIOUS simply by living with (and in spite of) VHL – while it may attack our bodies and those whom we love, we must remember that we are NOT simply “VHL patients” – we are people who are AFFECTED by it, not DEFEATED by it. My Mom died due to a complication related to her VHL brain lesions, but, I still consider her a “VICTOR” because she lived a full life filled with family, love, laughter whenever possible, and she remains a beacon to those of us who knew her. I refuse to say VHL “defeated” her, because it didn’t. She never let it do so. I strive to do the same.

## Pheo Survey

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**Figure 1: What DNA diagnosis was known before and after this experience?**



People were asked to respond to an online survey at SurveyMonkey.com prepared by Joyce Graff and Sue Buckley. Inspiration for this survey was provided by ten people that Joyce and Sue had been in touch with by telephone for up to 14 months, working to help them get a diagnosis of their symptoms. The barriers they were running into seemed ridiculously impossible. Even with a family history of pheos and a genetic diagnosis of VHL, some of these people had experienced doctors who refused to run the tests for pheo, ran them incorrectly, or failed to interpret the results. More than one had been told multiple times that “it can’t be a pheo, it’s too rare.”

The survey was launched in order to determine how widespread these issues might be, and to report to the International Symposium on Pheochromocytoma and Paraganglioma, being held in September in Paris, asking the doctors there to help fill some of the knowledge gaps in the field. The attendees of this conference include the world’s top experts on pheochromocytoma. The gap between their expert knowledge and the knowledge about pheos of the average doctor in the field is a serious problem for patients. While expert care exists, getting the patient from the street into the office of a doctor who can really help is a major hurdle.

We asked patients to describe their experience getting a diagnosis of their first pheo/para, or their most difficult experience if it was not the first. A number of major themes emerged.

### **Symptoms lead and mislead**

The most commonly known symptoms of pheo are known as the “classic triad”: headaches, heavy sweating, and high blood pressure and/or palpitations. It is not necessary to have all three. 187 respondents had two or more of the “classic triad” symptoms; 12 had all three.

102 respondents had a genetic diagnosis in hand. Another 20 had a family history of pheos. Yet only 7 pheos were found through routine screening.

It took an average of 3.5 years for people to get a diagnosis of pheo, with some people going 10-28 years before they received a diagnosis.

5% of people with pheos had none of these symptoms at all even when they had a visible lump in the area of the head and neck. This is actually not unusual for people with paragangliomas. One person commented: “I saw a GP for several years, then age 19 an ENT took out my tonsils but I still had lumps, so I went to a cardiologist who sent me to a plastic surgeon for a ‘snip-snip’ surgery of what they thought was a gland but it turned out to be a tumor of the carotid body.”

### **Regular screening saves lives and reduces long-term damage**

People who knew they had a familial risk factor and were going through regular screening did the best. Many experienced few if any symptoms. The pheo was found on a regular scan or through regular blood or urine testing, and treatment was performed in a timely manner. They also reported the best outcomes— all symptoms resolved completely, and they went on with their lives.

### **Delayed diagnosis hurts**

During the time people were waiting for their diagnosis, people reported many serious issues. First, of course, their symptoms worsened, making it difficult to concentrate, undermining their energy and stamina. As the tumors grew, serious emotional fragility developed, sometimes resulting in explosive temper which caused problems at work and in relationships. Even worse, the fact that their doctors did not believe they were sick, or accused them of using drugs, or of hypochondria or other psychiatric disorders had a severe impact on their feelings of self-worth and frequently led to feelings of helplessness and hopelessness. Many said they felt they had lost control of their lives. People with such advanced tumors often had some of the symptoms even after the tumor was removed.

### **Children do get pheos**

Some of the reports in the medical literature claim that young children do not get pheos, with some physicians declaring that it is not necessary to test children under 5 years old for pheo. In this survey, 25% of respondents had their first symptoms before age 15, 5% of them before age 6. While the average age of onset of symptoms was 28.3 years, the range was 0-82, and 13 respondents had their first symptoms before the age of 6, with one diagnosed and removed before the first birthday.

Parents who knew the genetic risk factors knew to refuse a doctor’s declaration that the child was making it up or trying to get out of school. Those who immediately sought another opinion from

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**Pheo Survey**

*Continued from Page 1*

someone with experience in pheos or in the known genetic condition were able to get timely help for their child. Children who struggled for years with these symptoms reported feeling depressed, being labeled by teachers as “a bad kid,” sometimes labeled as having ADD or autism, being angry, and/or losing friends.

**No one believed I was sick**

As people read our checklist of symptoms that might occur, several were surprised to realize they could be indicative of a pheo. Some said they were embarrassed to discuss some of these symptoms with their doctor, not thinking they were related: heavy sweating, constipation or chronic diarrhea, nervous tremors or tics, anxiety or feelings of doom. Dizziness, fatigue, and headaches were usually reported.

**Symptoms can lead doctors astray**

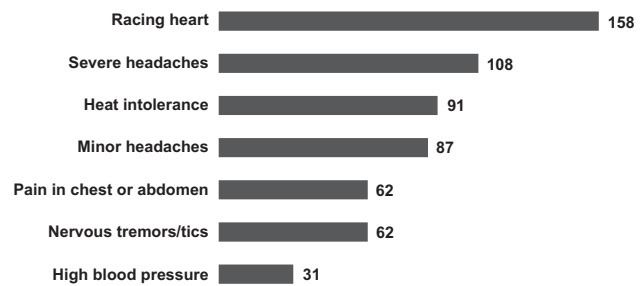
In his book “How Doctors Think,” Dr. Jerome Groopman reports that there is a phenomenon in medicine today which he calls the “zebra retreat” to describe a doctor’s shying away from a rare diagnosis. “Powerful forces in modern medicine discourage hunting for them. Often the laboratory tests and procedures needed to pin down an arcane diagnosis are hard to perform, highly specialized, and expensive. In an era of cost containment, when insurers and managed care plans scrutinize how much physicians spend on any one patient, doctors have a strong disincentive to pursue ideas that are ‘out there.’” Instead, the tendency is to look first to the most common conditions – the kinds of things this doctor sees every day. It takes time, attention, and courage for a physician to look beyond the obvious and arrive at a diagnosis of any rare disease.

In the case of pheos, the symptoms legitimately reported seem to have a tendency to route many doctors’ thinking toward one of heart disease or psychological issues. Here is why.

**Heart disease**

The chemicals generated by the pheo may cause the heart to race, the blood pressure to become erratic, nervous tics, and/or moderate to severe headaches, all of which might raise concerns of a heart attack or stroke (Figure 2). In fact, the pheo overworks the cardiovascular system and can in some cases lead to heart disease or stroke. However, once medications to slow the heart or handle angina are in the system, the best diagnostic tests for pheo may not work – there may be a “false negative” report – the test will say there is no pheo, but in fact the results are false. This makes it much more difficult to diagnose a pheo.

**Figure 2: 229 of 234 people with symptoms had one or more symptoms of heart attack**

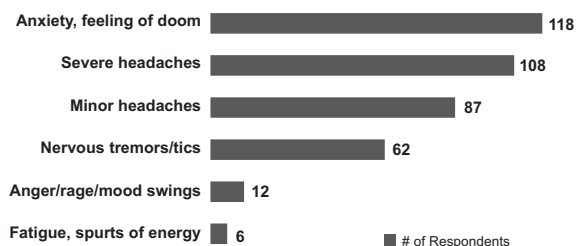


**Psychological issues**

When patients report anxiety, panic attacks, feelings of doom, fatigue, sometimes alternating with spurts of boundless energy, and mood swings for no good reason, it is logical to think this person is under stress at home, work or school, or has some more serious psychological issue going on (Figure 3). Many people were referred for psychiatric counseling and/or prescribed drugs. In two cases the psychiatrist identified that there was an underlying physical cause and sent the patient for testing that did identify the pheo. But more often the mood-altering or anti-psychotic drugs cause a false-negative test for a pheo.

Ideally the tests for a pheo should be run BEFORE prescribing medications for anxiety. More often, the thought to run the pheo testing occurs after these psych meds are already in the bloodstream.

**Figure 3: 174 of 234 people with symptoms had one or more symptoms of psychiatric issues**



**Pregnancy is a particularly dangerous time to have a pheo**

Five women in our study reported having pheos during pregnancy. The initial diagnosis was pre-eclampsia or toxemia, but fortunately most of the obstetricians consulted by these patients recognized that there was more going on, and/or sent the woman to a high-risk obstetrician who recognized the problem. In two cases the baby died. Women with one of these risk factors who becomes pregnant or is considering becoming pregnant should get tested for a pheo as soon as possible. It is possible to remove a pheo during the early stages of pregnancy without harm to the baby. However the longer the

baby lives with the hormones generated by the pheo, the greater the potential harm to mother and child. Childbirth with a pheo in place is potentially life-threatening both to mother and child.

### ***Time is the enemy***

As noted earlier, when pheos are diagnosed at early stages, before or at the beginning of the onset of symptoms, proper treatment usually results in full recovery.

As the tumor grows and injects larger and larger amounts of hormones into the bloodstream, symptoms worsen and often affect the individual's energy, mood, temper, and thus their interactions with other people. People who waited years for a diagnosis reported problems in school, in the workplace, and in relationships. This in turn sometimes results in divorce or loss of work, which might also mean loss of health insurance and serious financial problems. Loss of health insurance results in greater difficulty in accessing the medical attention needed to diagnose a pheo. It also results in loss of self-esteem and can lead to self-destructive behaviors. Here are some quotes from people who waited 3+ years to get a diagnosis:

- Out of work since January 2011 with symptoms they now think are a pheo. I work for a huge hospital, but 6 months after you go out on disability they terminate you and make you pay COBRA insurance at exorbitant prices.
- Severe emotional trauma within the family unit by constant disregard by health professionals and being made to feel like idiots when clearly something serious was occurring.
- The first pheo took 3 years to find. I thought I had major psychiatric issues during that time.
- If the doctors tell you often enough that you're crazy, you begin to believe it. Certainly my wife believed them and left with the kids.
- I found it difficult to control my anger when my adrenaline spiked (recognized it after diagnosis)
- Anxiety so bad that at one time I was suicidal and even self-medicated with alcohol and felt better when I did this. As soon as I got sober, the issues came back.

### ***Preparing for the surgery***

We know that "blocking" is important before surgery, administering drugs to block the negative effects of the pheo and keep the heart rate at a manageable level for the surgeon and anesthesiologist, so that you will come safely through the surgery. Four times patients were sent quickly into surgery. Twice the family knew to refuse and require proper blocking before the surgery.

What also is not routinely discussed is how the body will readjust to its "new normal" after the pheo is removed. Depending how long the pheo has been

pumping drugs into your system, your body may need some weeks or months to readjust. You may feel strange and need to make a special effort to calm yourself. Just know that this is par for the course, you will get through this, and your body will achieve its new normal in the course of things.

### ***How to protect yourself***

As families, we can educate ourselves, and make sure that when we experience this kind of symptom or see a family member going through this kind of downward spiral, we take action immediately, advocate for ourselves and our loved ones, seek expert help, and get to a timely diagnosis.

However, at the same time, we need help from the experts in educating the medical community. Respondents to this survey contacted an average of 5.5 different kinds of doctors each before getting a diagnosis – often several doctors in each specialty area. The top kinds of physicians consulted were: general practitioners or internists, endocrinologists, and Emergency Room physicians. Pediatricians and obstetricians/gynecologists are also on the front lines of care for children and pregnant women. The knowledge and experience of these specialists with pheos and the genetic conditions that can cause them tends to be sparse on the ground. Never hesitate to seek a second – or third – opinion, and to ask or check the resumes of physicians to see what they know about pheos.

Because of the possible misdirection that our symptoms may present, it is important that cardiologists and psychiatrists also know to think of a possible pheo. In some cases, the patient's short fuse sometimes caused less than polite behaviors in the doctor's office. Instead of being offended, it would be good if the doctor considered the possibility that this is a symptom. Certainly within the family we need to acknowledge when behavior changes, and see it as a possible symptom that something is wrong medically and needs to be checked out. While the doctor sees what occurs during that 12-minute appointment, family and friends who have known this person for years can notice the changes much more readily. We know when behavior is not normal for this person.

Educating yourself is your best defense for yourself and your family members. Twenty percent of people with VHL may get a pheo, and in some families the risk is higher (or lower). People with SDH mutations are likely to get even more pheos and paragangliomas. With knowledge and early diagnosis, we can avoid the worst consequences of these conditions and live normal and happy lives.

To see the patient survey report, go to:

<http://www.vhl.org/pheo/pheo-survey.pdf>.

The doctor survey report for the pheo survey is at:

<http://www.vhl.org/pheo/pheo-med-report.pdf>.

# How about some Chapstick?

*Submitted by Amanda H., DE*

It is important to figure out the difference between sympathy, support, and pity. What others give is not pity – only your perception makes it pity. If you perceive it and accept it as love and support you will be powerful. If you see it only as pity and reject it, you will be trapped in a dark place with no light to show the way out. People who accept love and support are stronger. They can fight diseases that nobody thought they could fight; they can recover faster and heal in ways that amaze and astound doctors and leave them with no solid answer as to why. It has been proven in studies time and time again. The truth is you can't count on answers. Answers are always changing and not even the smartest docs in the world have all the answers. But when people offer support and care and love, you can count on that like a rock. It doesn't change and it is always there.

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## ***People who accept love and support are stronger.***

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When I got my infection I was strong at first – but I got lost in it – strength turned into a trap. I needed two things to get out of it. I did need answers, but I also needed the care of a stranger.

I was pretty listless even after they started treating me. The doctors didn't know why. The infection was under control; I should have been getting better. I was depressed. I didn't think I would ever get better. I spent 11 days alternating between lying there staring at walls, without even the energy to watch TV, and dragging myself out of bed to get new vomit basins and have my sheets changed because I had no control over my bodily functions or dignity. The doctors kept pumping fluids and electrolytes into me, sending me for scans, and making me drink vile concoctions for the scans, even though I begged them not to make me drink something that would only make me more ill. They tried to put an NG feeding tube in me, and they were somewhat successful, only I felt like I was choking so they pulled it back out, after which I utterly refused it.

After a while the nurses started to leave me alone. Nobody came by to encourage me to walk anymore or get out of my bed and sit up, let alone wash my hair or brush my teeth. It started taking longer for them to respond to my call buttons. The doctors were stymied, and I was in no real mortal danger, so

they seemed to make fewer, briefer appearances. I felt weak and helpless. I just wanted it to be over.

I know what it's like to want answers, but I can tell you that when you're in that kind of a situation, answers are the last thing you care about. You want relief – a light at the end of the tunnel. Answers eventually healed my body, but my soul was also suffering, and answers don't heal the soul. The answer and the light came at about the same time on the 10th day. The surgeons were finally stumped enough that they called my endocrinologist in to visit me. I love endocrinologists. They listen. He talked to me about what was going on and realized quite quickly that I was not getting my proper doses of cortisone (because I had had my adrenal glands removed in the 90s). He found the answer and left orders for the necessary changes.

On the same day a woman came to my room. She wasn't a nurse. I'm still not sure who she was. She was elderly and looked at me with kind and sympathetic eyes. She asked if I needed anything. I felt like I did not want her pity. I looked away and told her "no". I didn't want to need anyone. I didn't want to be a burden. I was going to stoically get thru it on my own. I had even started telling my husband not to bother coming in, since there was nothing he could do.

The woman, however, did not give up. "Maybe some Chapstick?" She asked. Suddenly I saw the light at the end of the tunnel. Only moments before, I had really longed for a tube of Chapstick. I was dehydrated, not allowed to even drink water or suck on an ice chip, and my lips were very dry and cracked. I would have given anything for Chapstick. But I couldn't get it for myself and I hadn't wanted to ask anyone. And here she was, a stranger, who empathized with me enough to know exactly what I needed at that moment. I felt like someone understood and sympathized, and I realized that to say "yes, please help me" was not being weak. In that single moment she helped me find my way out of the dark place I had been holed up in.

I reconnected with another human and I let her see my "weakness" and my need. And after that, I had hope. I knew I would get better. I realized that the pain and suffering of surgery and infection would eventually be barely even a memory. By letting go of my need to be "strong", I found real strength again. You might explain my rapid turnaround (within 1 day, I had completely recovered) by the fact that I was getting the proper meds again, but I know in my heart that I also needed to let go of all the pent up anguish inside me, which I never could have done without admitting to myself that I needed the care and support of someone else.

There are times to be strong and there are times to lean on others. Only with both can we find true strength.

# Interview with Walter Wolff

April 7, 2011

*Walter Wolff is a jazz pianist based in The Hague, the Netherlands. He originally comes from Finland. Walter is the first person with VHL in his family.*

*This interview was conducted in English.*

**RG:** Can you tell me a little about how you came to the Netherlands?

**WW:** I had studied for two years at the conservatory in Helsinki [Finland] and I was not happy with my school there. A friend of mine was at the conservatory in Groningen [Netherlands], so I went for a visit. I was able to take an entrance exam while I was there and was accepted. My friend urged me to take the entrance exam at the conservatory in The Hague too, which I did. I was accepted there also. I chose to go to The Hague [Netherlands].

**RG:** Tell me about your work now.

**WW:** Unfortunately, the budget cuts are having a big impact on all the arts. Sponsors are pulling out of festivals, so there are fewer festivals. Music programs are being cut at schools. There are fewer gigs. I spend at least 50% of my working time on getting and arranging work; that takes a lot of energy. It is tough for everyone in the business, but these days you need "the whole package" to survive. I like the variety that comes with many aspects of my job, from the administration to making sure the posters get out okay, to the actual performing. I am doing relatively okay for now; I have two teaching jobs and am working with different groups regularly.

**RG:** What was your first experience with VHL?

**WW:** I got a brain tumor in my second or third year at the conservatory in The Hague. I thought this was bad luck, but it could happen to anyone. I could NEVER have expected this. When I needed a second big operation on my back (for a spinal hemangioma), the doctor thought it might be VHL and at that point I had a DNA diagnosis. When I heard that I had VHL, I thought, "okay, I do the checks once a year," and I just went back into my studies. I only slowly realized what it really was about. My mother was more concerned and did the research to understand the implications of having VHL. She has been very involved from the beginning.

**RG:** Did you get adequate information?

**WW:** The geneticist described the genetics but didn't explain the course of the disease or what I might get. I would have liked to have someone come and talk to me a few weeks later about what VHL really is.

**RG:** Did VHL affect the choices you made with regards to education and career?

**WW:** I had already made my career choice before I was diagnosed with VHL. Who knows if I would have chosen differently if I had known I had VHL first.

**RG:** You mentioned that you have had several surgeries in these last years for brain hemangiomas. How do VHL-related problems affect your music? I can imagine that fine motor skills could be affected.

**WW:** My left hand is definitely weaker since the last operation. It probably has about 60% of its previous strength. Fortunately, I have been able to adapt as a pianist, so my music still sounds good. If my right hand eventually experiences similar problems, I might have to make some big changes, perhaps stop being a piano player. I can adapt to still work, for example, I can imagine doing other things in the same field. Maybe I would write more music instead of playing it. I am going on the assumption that it is a matter of WHEN this will happen not IF.

I am very fortunate and lucky to do what I like. Right now, I am doing okay, and I don't want to waste time. In that respect, you could say that having VHL has been good to me; I stay active and appreciate my abilities and good fortune here and now. Artistic blackout can happen to anyone. But if I feel that way, I just say to myself: "come on Walter, pull yourself together." VHL has forced me to develop some psychological strength. It makes me aware of the quality in my life.

**RG:** As a musician, I can imagine that you are used to communicating emotion more than someone who works in the service sector. Does music help you deal with stress in general?

**WW:** Communicating emotion works two ways. Playing music helps me deal with let-downs or feeling blue. It helps me deal with emotional stress; that definitely feeds into the music. It's abstract, but sometimes I want to play out emotion through music and make the audience laugh, or make them be upset, or even cry. There is some conflict with remaining professional at times, but that balance comes with practice.



Walter Wolff

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**Walter Wolff Interview***Continued from previous page*

**RG:** Have you ever experienced discrimination in employment, insurance, mortgage lending, or support?

**WW:** I have never experienced any issues with life insurance or mortgage, but at this stage in my life, I haven't really been confronted with those needs. I don't own a house.

I like my doctors in Finland and I fly back to Finland for my periodic screens. My doctors know about VHL there, and I trust them. Although we can discuss medical issues well with them, talking with other people affected by VHL can really help with the practical points. For example, at the Dutch Annual Meeting in Breukelen a few weeks ago, my girlfriend and I talked with a man who had VHL who told me how he got a mortgage on his house. I had never met anyone else with VHL before.

To hear Walter's music or check out his next gig see: <http://www.walterwolffmusic.com/>

His CD or digital album can be purchased here:

<http://wolff-angiuli-fryland.bandcamp.com/album/prelude>

## New Medical Advisory Board members



*Dr. Libutti*

Dr. Steven Libutti and Dr. Gennady Bratslavsky are joining the Medical Advisory Board of the VHL Family Alliance. Both of these fine physicians have spent many years on the VHL team at the U.S. National Institutes of Health, where they have made important contributions to learning about VHL. They are taking that knowledge to their new positions in the field, and are building a team around themselves that will have access to their knowledge about VHL.

Dr. Libutti is chairman of the Cancer Institute at Montefiore Hospital in New York City, affiliated with Albert Einstein School of Medicine. His research at NCI focused on the formation of new blood vessels, which nourish tumors, as well as the interaction among tumor cells, endothelial cells, and components of the tumor microenvironment that influence tumor growth and spread. He has published widely on the pancreatic and neuroendocrine aspects of VHL, including pheochromocytoma and paraganglioma. He has organized a team of physicians to deliver comprehensive care for people with VHL which is now one of our three clinical care centers in New York City. See link below for more information: [www.vhl.org/newsletter/vhl2011/11cg\\_libutti.php](http://www.vhl.org/newsletter/vhl2011/11cg_libutti.php)

Dr. Bratslavsky is now the chairman of Urology at the State University of New York (SUNY) Upstate Medical Center in Syracuse, New York. Dr. Bratslavsky knows Upstate New York well, as a graduate of Siena College and Albany Medical College. At the NCI, he directed the urology fellowship program in robotic surgery and built an enviable reputation as an investigator, charismatic teacher, devoted physician, and skillful and innovative surgeon. He represented VHL at a conference in Moscow last year, and has recently published a study of the gene expression of large versus small tumors, confirming through genetic studies that significant additional genetic changes occur as the tumor gets larger and moves toward gaining metastatic potential. See link below: [www.vhl.org/newsletter/vhl2011/11ch\\_bratslavsky.php](http://www.vhl.org/newsletter/vhl2011/11ch_bratslavsky.php)



*Dr. Bratslavsky*

We are honored to add these two respected physicians to our Medical Advisory Board.

## Endo 2011 Meeting & Expo

*By Susan Milliken*

On June 4, 2011, I attended the 93rd Annual Meeting and Expo in Boston, MA. I set up a small display at a table where the Pheo Paratroopers were kind enough to share their display table.



While our display went mostly unnoticed (after all, VHL is so rare!), there were a few medical professionals who came over to talk to me about patients they had with VHL or pheochromocytomas.

I heard several speakers on pheochromocytomas and kidney cancer as well as a very interesting talk on hunting down genetic mutations and the problems doctors and researchers encounter in trying to define the gene that causes a genetic disease.

In summary, the speaker acknowledged that there are many biological processes yet unidentified. These gaps in our knowledge contribute to the failure of treatments in the clinic. While we are focusing on the one gene we feel is the culprit, there might be another gene hiding in the shadows that is also influencing the process. Also, we don't always know the role of modifier genes in genetics. Why does one person with VHL get many tumors while others don't? Why do some get pheos and others are more prone to tumors in the brain and spinal cord? The reason people may develop fewer tumors could be differences in some additional "protective" genes.

That's when a researcher asked the question about protective genes. He wondered by we concentrate so much on the disease gene, but we don't concentrate on the genes that could strengthen our defenses and protect us. I found this very interesting. Instead of finding a drug to get rid of the tumors after they form, perhaps we can find something that will prevent us from getting tumors at all!

Overall, the Expo was extremely well attended by doctors, researchers, medical students, and other patient advocacy groups, and the particular presentations regarding neuroendocrine genetics and pheos were practically overflowing. Hopefully, this will lead to better recognition of all kinds of pheos, and improvements in diagnosing VHL.

## Altheada Johnson—A true pioneer

By Joyce Graff



*Altheada and Fred Johnson*

When we started the VHL Family Alliance in 1993, there were many myths about who got VHL. Some families had been told it only affected males, others that it only affected females. Some thought you had to be German. My personal favorite was a story that VHL came from Sweden, and that some enterprising Viking more than 400 years ago carried VHL to all parts of the globe.

When we held our first VHL meeting in Massachusetts, most of the people in the room had never met another person with VHL outside their own family. And then Altheada and Fred Johnson rolled into the room, showing us certain proof that people outside our own families, outside our own ethnic groups, also got VHL. We welcomed the first African Americans to our VHL family.

Throughout the years, both Altheada and Fred have been staunch supporters of this Alliance. Altheada traveled to meetings around the country, speaking to professional and lay groups about VHL, helping to raise the visibility of the multi-ethnic nature of this disease. She was a hotline volunteer since 1994, and chaired the Hotline Committee 2002–2010. A retired dietitian, she helped field questions about nutrition, and made instructional wheelchair cooking videos for the International Center for the Disabled (ICD) in New York. She also organized a group of disabled artists and advocated for them. Their work is now displayed in the corridors of the ICD.

Altheada's father died of a brain tumor in October of 1966. Her brother also died of a brain tumor in February, 1969. For the first time, the doctors called it VHL. The family was told that VHL only affected males. With another four daughters at home, Altheada's mother Lillian thought they were done with VHL. The girls grew and thrived, Lillian remarried a wonderful man who helped her nurture

the girls, and all four girls went off to college and set up happy lives for themselves. Altheada married the love of her life, Fred Johnson, and enjoyed jogging, tennis and dancing with him. She and her sister Joyce ran the Legg's Mini Marathon in New York.



*Altheada and Joyce crossing the finish line at the Legg's MiniMarathon in New York*

She was working as a dietitian at the Beth Israel Medical Center in Newark, New Jersey, when she began noticing pains in her legs. She asked doctors, but did not get a diagnosis. She exercised, but nothing she did made it better. Finally she saw a neurologist who diagnosed a problem in her spinal cord. Following the surgery, she spent a year in rehab and was able to get back on her feet. During this time the diagnosis came down—this was VHL, the same disease that had taken her father and her brother. Then another tumor struck, and a second surgery meant another stint of many months in rehab. Throughout all this time, her family and especially her husband visited her every day, nourishing her with their love and their faith.

By the time we met in 1994, Altheada was in a wheelchair. Like all of us, she was eager to learn more about VHL—what else might it mean in her own family? The four girls who had thought they were safe from VHL were no longer safe. When DNA testing became available in the mid-90's, her sister Kathy was found also to have VHL.

**Altheada Johnson**

*Continued from previous page*

She joined our team to build the VHL Family Alliance and served 12 years on our Board. One of the highlights of our 17-year association was a trip together to Johannesburg, where we attended the first VHL meeting in South Africa. At the time, all the other faces in the room were white – mostly descendants of Dutch and German immigrants whose history in South Africa parallels in many ways the history of European immigrants to America and Australia. A Founder Effect has been found among the Dutch settlers, showing that VHL existed among their Dutch ancestors before they emigrated to Africa in the 17th century. Both Fred and Altheada spoke to the group, and were embraced by these people from another culture across the world, bonded together by a single gene.

Our experience there pointed out to us the disparity in health care in South Africa where, until recently, better medical care has been available to whites than to blacks. Such disparities are not unique to South Africa, but are clear even in the U.S. This is changing and, since our visit, more black South Africans have been diagnosed with VHL, along with Africans in Ghana, Senegal, Central African Republic, and many North African countries.

Altheada died in May of 2010 after a long and energetic battle with VHL. Her pioneering spirit will always remain with me, strong in the face of great odds, determined to make VHL better for everyone, and especially for those many people of African descent all around the world who may not yet know

what disease they are fighting, but who deserve a chance to know and to learn how to protect themselves.

Fred Johnson continues on our Board of Directors, sharing his own knowledge and experience as a 30-year caregiver for a wheelchair-bound wife, supporting her own campaign to change the world for people with VHL. He continues to



*Altheada (second from right) singing with her sisters as teens*

provide support and coaching for Altheada’s niece and nephew who are affected by VHL, and to share his expertise in training and communications with VHLFA.

One of my strongest memories of Altheada is of her family at her funeral, sad in their loss, strong in their faith, and yet joyous in their celebration of Altheada’s life, was one of strength and passion.

A fund for advancing research has been established in her name. Please celebrate her life with us by making a donation to the Altheada LaVerne Johnson Research Fund.

For more glimpses into her life, please see the interviews she did for the Powerful Patient, especially around the African trip. [www.powerfulpatient.org/archive/2008/08n\\_south\\_africa.php](http://www.powerfulpatient.org/archive/2008/08n_south_africa.php)

***Donations in memory of Altheada LaVerne Johnson may be made through her First Giving page at: <http://www.firstgiving.com/fundraiser/robin-cochrane/altheada> or send a check to VHL.***



VHL Family Alliance special:  
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# Remembering Peggy and Don Marshall

By Amy Gray Light

While attending the VHL regional conference in Houston this June – which was extraordinarily well-run – our esteemed facilitator, Joyce Graff, introduced me at the end of the day to the participants as a “pioneer,” referencing my 27 years’ experience with VHL. I find the word more gratifying than ‘survivor;’ it makes me feel stronger



*Peggy and Don Marshall*

and pro-active in navigating this strange journey. But, as much as anyone could call me a pioneer because of frontline experience, to *my* mind, it is the late Peggy Marshall and her late husband Don, who I consider to be true pioneers. Peggy and Don were a unified team – I heard many times Peggy say she couldn’t have managed without him nor he without her – so it was no surprise he died shortly after she did.

Whether or not you were lucky enough to meet Peggy in person or through the telephone as she ran the hotline for the *VHL Connections* they both established, talking with Peggy was always a positive experience, no matter how difficult the subject.

She and Don started *VHL Connections* to emphasize the individual aspect of people affected

by VHL, who wanted – needed – to talk to people familiar with what they were experiencing and who knew what to expect. She and her hot-line helpers offered support, information, knowledge, and resources. Peggy loved to talk – no phone conversation was under 15 minutes, and most were closer to an hour – and her gentle, soothing voice enabled you to feel better no matter the situation. Her genuine concern for your well-being and that of your family made you relax in the knowledge that someone knew and cared what you were going through.

Peggy asked me to write a column every other issue shortly after the *VHL Connections* newsletter was launched. Uncertain what would be required – she didn’t put any specifications onto the assignment – I nevertheless agreed. I could never say ‘no’ to Peggy.

She and her family had been affected by VHL for generations, and we knew Don was also experiencing challenging health issues, still, it was with a sinking feeling of disbelief we heard of her death, and Don’s shortly thereafter, because Peggy was the epitome of a lady graced with indomitable spirit. I selfishly thought she would go on forever – or at least into a ripe old age.

Peggy was a true pioneer in the sense of the word, and she will be truly missed. One whose good works for our cause has positively affected many. Peggy has left the world a better place for her contributions. I wish I had gotten the chance to thank her once again for her time, energy, and thoughtfulness.

The best legacy I can think of, and of which she would approve, is to try to continue reaching out to others.

*Amy Gray Light lives in AR where she and her husband run Wing Spur (wingspur.org), a non-profit wild mustang sanctuary. Since 1997 Amy has been on medical disability and is now a freelance writer and editor. Her email is orphicaeg@windstream.net.*

**Donations in memory of Peggy and Don may be made through their First Giving page at: [http://www.firstgiving.com/fundraiser/VHLboard/peggy\\_marshall](http://www.firstgiving.com/fundraiser/VHLboard/peggy_marshall) or send a check to the VHL Family Alliance at 2001 Beacon St., Suite 208, Boston, MA 02135.**

**Join us for the 10th International  
Medical Symposium on VHL**

**January 26-29, 2012 in Houston**

*See page 16 for details*

## ***Message from Ilene Sussman, Executive Director***

I am honored to be able to serve the VHL Family Alliance. Over the coming months, I plan to learn more about VHL and ways that we can work together to improve diagnosis, treatment, and quality of life of those affected. Increasing awareness and education among the medical community, as well as the general public, is key to achieving the organization's mission.

Enhanced methods for diagnosis and treatment are essential! I know that with your help and support, together, we can encourage and stimulate advancement in medical research in order to achieve this goal.

I am interested in learning more about the members of the VHL Family Alliance, including ways that the organization can better serve you, as well as fulfill our mission. Please feel free to contact me with your input, either by phone (800-767-4845) or email (ilene@vhl.org). I look forward to hearing from you!



Ilene Sussman

## **Glacial Energy: Electricity for your business, charity for VHL**

If you own a business and would like another way to help, we have an opportunity to help each other. Glacial Energy has been providing support for the VHL Family Alliance for the past 18 months.

Glacial Energy is now offering discounted commercial electricity to our family of supporters with the ability to have a portion of your monthly bill for electricity donated to the VHL Family Alliance. Your monthly electric bill can now help support research, diagnosis, education and support for families dealing with von Hippel-Lindau. Your donation through this program adds no cost to the electricity supply and Glacial Energy saves the average business 10-15% yearly on their cost of electricity. We help each other through a simple change in supplier.

Glacial Energy is a licensed supplier of electricity in 14 states including CA, MA, ME, NH, RI, NY, NJ,

IL, MD, DE, PA, OH, MI, TX and Washington, DC. Glacial Energy is a green company with the ability to supply both standard and renewable energy products through the renewable energy credit program. If you would like to know more about how you can help the VHL Family Alliance and your business, please call Jeff Hickson BDM at 508-341-0214 or e-mail at Jeff.Hickson@GlacialEnergy.com. For more information you can also go to their website at [www.GlacialEnergy.com](http://www.GlacialEnergy.com).

Smitty's Cinemas signed up last year to donate a portion of their energy bills through Glacial Energy, which has already brought more than \$1000 to VHLFA. Many thanks to all the good folks at Smitty's! Please support the Smitty's Cinema near you. See <http://www.smittyscinema.com>.

## ***How can you help support VHL?***

**Visit: <http://www.vhl.org/aboutvhl/famindex.php#help>**

# Fun and fundraising

## Beth Smith's Triathlon

by Beth Smith

Hello friends!!

I did it!!! I completed the Dam Triathlon (The Beaver Strikes Back) in Amesbury, MA on July 9, 2011 in 1 hour and 30 minutes, 10 minutes better than last year's time. The weather was perfect and the race was a lot of fun. I



am already looking forward to next year. I just wanted to take a moment to thank you again for your generous donation to VHL Family Alliance. I've managed to raise \$3,564 so far for VHL Family Alliance. I am so grateful for your generosity each year. Thanks to your help!

Below is my story about VHL and the impact it has had on my family.

I was diagnosed with VHL when I was 20 years old. I didn't have any symptoms, but lost my father when I was an infant to the disease. My oldest brother David was also battling VHL at the time. He fought for over ten years, but eventually lost his battle 7 years ago at the age of 38. I was given the choice of DNA testing and decided that I needed to know. The "not-knowing" was worse for me. When I received the news that I did in fact have VHL, I was upset, but decided to use the diagnosis to empower rather than overwhelm me.

Since that time, I have been having yearly screenings, MRI's and eye exams. I have been extremely lucky to this point with only a few small tumors in my brain and one in my pancreas. Right now, we are just watching them closely. I try to eat right and exercise to keep my body strong and healthy so that it has its best shot at fighting this disease.

I also have three small children. My 6 and 4 year old both have VHL as well. We had them DNA tested at 6 months of age, again deciding that knowledge is power. It is not the diagnosis that we had hoped for, but we now know to have them screened regularly and we will deal with issues as they appear.

Thankfully, at this time they are both happy, healthy children. I hope that I can be an example for them as they get older and have to face this illness. I also try to be an active participant in fighting this disease. I spread the word to everyone I know and try to raise money at every opportunity.

## Rick Bracey 29er Softball Tournament 2011

*Bracey/Hazeldine families & the 29er Tournament Committee*

What an amazing day and a great tribute to Rick. We were challenged with some adversity (rain, puddles, and not enough Advil). Then in true Ricky fashion, we finished off with sunshine and a great final between the Rummages & the Big Dogs who came off the porch to win the tournament! The tournament was filled with friends and family having fun while still being competitive, exactly how Rick would have liked it.



An estimated 170 attended this year's Rick Bracey 29er Softball Tournament – fun & fundraising event on Saturday, June 18th at Softball City. Thanks to the overwhelming support by all who participated and donated, we raised an unprecedented \$11,700 – more than doubling our goal, an amazing amount being donated to the Canadian VHL (von Hippel-Lindau) Family Alliance. Please keep your eye out for the Peace Arch News for coverage of our tournament.

Thank you again to all our committee members, volunteers, coaches, and our dynamite 50/50 sales girls! We would also like to thank the VHL community, friends, and family who supported us in our goal of raising awareness about VHL while having fun and fundraising.

Save the date! Next year's tournament will be held on Rick's birthday, Saturday, June 16th, 2012. Early registration will be key to ensure you are not disappointed. We will send registrations out in March, 2012.

We thank all those who participated and encourage you to visit [www.vhl.org](http://www.vhl.org) to learn more about this terrible disease.

## Shana's Mother's Day Run

*Exerpts from <http://www.vhlmymomandme.blogspot.com/>*

It started at the end of March. Shana wasn't feeling very good. Headaches, dizziness...the words that scare me the most. She went to the doctor, and then you have to wait for a referral that never comes.



On April 15th, she went to the ER. I got a call in the middle of the night that they were keeping her; there was a tumor and some cysts that they needed to remove.

As I hang up the phone, a dark cloud comes over me. I was remembering my mother's surgery last summer – dread, fear, sadness – and worry for my daughter. What she must be going through right now.

When my mother had her surgery, I knew she would be having surgery, but I never imagined it would be immediately. When I got to the hospital, she was sedated and tied to the bed. They said she was fiddling with the IV's. I knew that this is the way my mother saw – through her fingers – she wasn't fiddling; she was looking, and she was sedated. I hope she knew we were there. I kissed her and told her I'd be "right there" waiting for her to come back. I never saw her again. I couldn't let this happen with Shana!

We went to the Loma Linda University Medical Center in Loma Linda, California. After several wasted days and frustrating missteps by the hospital staff, they finally took her off to surgery. During the surgery, we got a text saying the surgeon wanted to speak with us! I've seen it on TV many times, but never experienced them calling us into a special room?!

The surgeon came in. I could barely talk, but I asked him, "Is she ok?" He said "yes, the other surgeons are closing." He said that everything went as planned. I gave him a big hug. We went back to the Waiting Room and waited for her to recover in the ICU.

I could see in her eyes that Shana was okay. She was tired, weak, and needed rest, so we limited the visit to just minutes.

The next day Shana had already been out of bed doing laps around the nurses' station. She only spent 12 hours in ICU. She is so strong – she amazes me!

She came home on Thursday...13 days in the hospital, 4 days after surgery.

I feel like I've been at the "starting line" of a race for the past 10 days. We planned a Mom's Day Run in memory of my mother and in honor of Shana. Shana was determined to be there, and she was (13 days after surgery). We had a good turnout despite the previous month. We raised \$1,500 for VHL!!!

After the Run, we went to the sand and had a moment with my mom. We miss her so much and know she is proud of us today. We will honor her memory every day, especially Mother's Day with the Mom's Day Run, raising money and awareness for VHL in her name!



## Outdoor Workout for VHL

*by Susan Milliken*

On Saturday, August 27th in Watertown, MA, Jeanine Babineau led a vigorous workout through the Ultimate Boot Camp to help find a cure for VHL. Twenty people signed up and worked up a good sweat, and then Maryanne and Jim hosted a raffle, which included a beautiful afghan that she made and a candle basket. I was so glad to be a part of a day that was led by such fun and energetic people.



## London Marathon Fundraiser

Chloe D's sister Jo completed the London Marathon on April 27, 2011. We raised an unprecedented total of £3400!

Massive thank you to every single person who put their hand in their pocket/wallet/bank account and for all the good luck/congratulations messages as well as all the prayers I needed to get round! It was definitely a once in a lifetime experience, not to be repeated! I also know this wonderful donation will be very much appreciated by the UK VHL support group.



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**Please join us at one or more of the following events coming up!**  
 see also [vhl.org/meetings](http://vhl.org/meetings)

## VHL Medical Symposium, January 27–29, 2012

We are very excited to announce the Tenth Biennial Medical Symposium on VHL, to be held in January 2012 in Houston, sponsored by the M.D. Anderson Cancer Center and the VHL Family Alliance. There will be sections on metabolomics, cilia centrosome regulation, epigenetics, VHL proteostasis and non VHL hereditary renal disorders. This will be a dynamic exchange of ideas seeking better ways to treat VHL and its member tumors.

Doctors can earn Continuing Medical Education (CME) credits, a maximum of 14.5 AMA PRA Category 1 credits.

### ABSTRACTS ARE DUE NOVEMBER 20, 2011.

Scientists: Submit abstracts to present your work in Basic, Translational, or Clinical research on VHL and related tumors (HLRCC, BHD, pheochromocytoma, paraganglioma). See <http://vhl.org/conf2012> for details.

**BOOK YOUR HOTEL ROOM NOW:** Hotel Zaza, 5701 Main Street, Houston, TX 713-526-1919. Ask for the special rate for the MD Anderson VHL Medical Conference (\$209).

### Arizona Chapter Meeting

*Sunday, November 20, 2011, 6:00 pm  
 Desert Ridge Marketplace, Scottsdale, AZ*

*Any interested can call or email Robert Kramer directly so he can get a head count for the reservation.*

**717 329 8398** or [us-az@vhl.org](mailto:us-az@vhl.org)

**AIR TRAVEL TO HOUSTON** may be booked with a special discount rate with Continental Airlines, 800-468-7022. Be sure to give them codes ZJMD and 325945.

### AGENDA:

- **Thursday, January 26, registration will be open 6-9 PM, followed by opening reception**
- **Friday, January 27, registration begins at 7 am, and the meetings run 8 am Friday through Sunday 2 pm, January 29.**

### NOTES FOR PATIENTS AND FAMILY MEMBERS:

Patients and family members are invited to attend all three days, on the understanding that the primary purpose of a Symposium is for the researchers to collaborate and move the research forward. No effort will be made to constrain the language of the presentations during Friday and Saturday. Sunday's meeting are being designed to be in more approachable language, and will allow for more interaction among the families.

Any patients and family members who would like to attend the first two days are invited to attend an optional half-day "VHL 101" introduction to the language and concepts that will be presented during the Symposium. Please register separately for VHL 101 by writing to Joyce Graff, [wellness@vhl.org](mailto:wellness@vhl.org).

**Special patient/family prices:** Sunday only: \$100 per person

**Full conference:** \$300 per person

Please check <http://vhl.org/meetings> for updates and directions or call the office, 800-767-4845, ext 4