



## **“Don’t Go There Unarmed” or “It’s Hard to be Taken Seriously in a Johnny”**

By Christine S. Lang, Executive Director, PATHS

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I have been a patient advocate for 26 years. If you are in the hospital or have a difficult physician visit, I am the person you want with you. Please understand that I only do this for family, and I share my knowledge by teaching others how to advocate and navigate the health care system. Just 2 weeks ago I had an interesting, and at some moments *scary*, reminder of what it is like to be a patient.

I have been working long hours and skipping meals over the past few months. We created PATHS this spring from the ground up and have all been extremely busy. I awoke one day last week with some uncomfortable symptoms. I took a few minutes to analyze them and diagnosed that I needed to eat. My calendar called for a networking breakfast just down the road so off I went. The symptoms did not subside with breakfast so I consulted with an RN at the functions and yes, it was off to the ER.

Because of the rush to the ER the copy of my medical records was left in my car. Usually in a medical setting, I am at the very top of my game, confident and effective as an advocate. But at this moment, I was the patient, pretty sick and scared, with my own advocate out of town....and wearing nothing but a johnny. Is any one every confident in a Johnny? I don’t think so! Over the course of 3 days, I was admitted twice, the second time within 4 hours of being released the first time. I received some excellent care at the hospital; one doctor went out of her way to find a diagnosis when the obvious conclusion tested negative. I also received some not so great care: never given my regular medications, yelled at by a doctor for asking questions about my tests and treatment plans and overmedicated for what they guessed was my condition.

I was alone and in a vulnerable position; and because I was the patient, I was not always listened to – so don’t let that happen to you. You never know when you may need your medical files – have copies everywhere, in your home, car, and briefcase. Why not put them on a flash drive on your key chain? There is something magical about having your medical records in a well prepared PHR – you get instant credibility and respect because you are giving the doctors that vital information needed to correctly treat and diagnose you. So be prepared, stick up for yourself and get your questions properly answered, and strongly consider attending one of our seminars. This episode served as a good reminder of how important it is to remain vigilant as a medical advocate, and how useful and effective the 7 Steps presented in the PATHS’ Advocacy Training Seminars can be.

**Question: What Scares Doctors?**

**Answer: Being the Patient**

### **Part 1 of a 6 part series**

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It's easy to imagine that doctors don't get sick. Surely the hygienic shield of the sterile white coat guards them from ever having to put on the flapping gown and flimsy bracelet, climb meekly into the crisp bed and be at the mercy of the U.S. health-care system. And if somehow they did enter the hospital as a patient, physicians ought to have every advantage: an insider's knowledge, access to top specialists, built-in second opinions, no waiting, no insane bureaucratic battles and no loss of identity or dignity when you turn into the "bilateral mastectomy in Room 402." But it doesn't usually work that way. While doctors are often in a better position than most of us to spot the hazards in the hospital and the holes in their care, they can't necessarily fix them. They can't even avoid them when they become patients themselves. When Dr. Lisa Friedman felt the lump in her breast in the summer of 2001, she did--nothing. "I just sat on it," she says, "because I clicked into the mode of being physician, not patient, and I thought, 'Most lumps are not cancer, I'll just watch this.'" That was her first mistake.

By September Friedman had watched long enough. An internist in a practice that covers much of southern Wisconsin, she went to her radiology department to schedule a mammogram. The administrators turned her down: her HMO paid for routine mammograms every two years, and she'd had one 18 months before. "I said, 'Wait a minute, I feel a lump. This is not routine.' They still wouldn't let me do it."

This is the stuff bad movies are made of. Friedman had to appeal to the HMO's board of directors. "I said, 'I'll pay for my own mammogram. Just let me get it done.'" She won her appeal and finally had the test. "They didn't even have to do a biopsy," she says. "The radiologist just looked at it and said, 'Oh, my God. You've got breast cancer.'"

The education of Lisa Friedman, patient, had begun. Like any other patient--and perhaps even more so--she had to drag information out of her physicians. "They were treating me like I was knowledgeable, but they weren't listening to me." When she found out that the cancer had spread to several places in one breast, Friedman told her surgeon there was no need to preserve her breast for cosmetic reasons; she was more concerned that the cancer be entirely removed. She asked for a mastectomy--but she was told that a lumpectomy would do the job fine. "I went along with it," she said. That was her second mistake. Her breast was riddled with tumors. "They ended up doing three lumpectomies. They were cutting away at my breast until I had no breast left. I said, 'Will you please take it all off?'"

Friedman's doctors weren't incompetent. They didn't operate on the wrong breast or give her the wrong drugs or commit any egregious medical errors--and that is the whole point. While there are bad doctors practicing bad medicine who go undetected, that's not what scares other physicians the most. Instead, they have watched the system become deformed over the years by fear of litigation, by insurance costs, by rising competition, by billowing bureaucracy and even by improvements in technology that introduce new risks even as they reduce old ones. So doctors resist having tests done if they aren't absolutely sure they are needed. They weigh the advantages of teaching hospitals at which you're more likely to find the genius diagnostician vs. community hospitals where you may be less likely to bring home a nasty hospital-acquired infection. They avoid having elective surgery in July, when the new doctors are just starting their internships in teaching hospitals, but recognize that older, more experienced physicians may not be up to date on the best standards of care.

Most doctors freely admit that they do everything they can to work the system. "As much as we all value fairness, if you think you can get some special attention for someone who's important to you ... I don't know anybody who would not play that card," says Michael McKee, vice chairman of psychology and psychiatry at the Cleveland Clinic. But talk to doctors about their experiences and you'll be surprised by how little power they have to bend the system to their will.

This is one abiding irony of progress. The most wondrous technology exists that can pinpoint the exact location of a tumor, thread a tiny catheter up into the brain to open a clogged artery, pulverize a kidney stone without breaking the skin. But the simple stuff--like getting an MRI on time, being given the right drugs at the right time, making sure everyone knows which side of your brain to operate on--can cause the biggest problems. "A patient with anything but the simplest needs is traversing a very complicated system across many handoffs and locations and players," says Dr. Donald Berwick, a pediatrician and president of the Institute for Healthcare Improvement. "And as the machine gets more complicated, there are more ways it can break."

For full article: <http://www.time.com/time/magazine/article/0,9171,1186553-1,00.html?artId=1186553?contType=article?chn=us>

## PATHS Live Radio Show

**10.a.m to 11 a.m**

**2<sup>nd</sup> & 4<sup>th</sup> Fridays**

**PATHS Health Journeys** will be a talk show where we interview professionals and patients/ families and hear their stories. We will share tips and advice, learning from their stories and experience. DivaToolbox.com is a fabulous website that offers all informative articles and updates, now they have created a radio station and are producing our show. . I welcome listeners to become participants and call in to share their stories and ask their questions by phone or computer. You connect at my host site link:

<http://www.divatoolbox.com/diva-toolbox-radio/hosts/1940-christine-s-lang-health-journeys.html>.

**From your phone:** Dial: (724) 444-7444 Enter: 65223 # (Call ID), Then Enter: 1 #

**From your computer:** <http://www.talkshoe.com/talkshoe/web/talkCast.jsp?masterId=65223&cmd=tc>

**Starting Friday, October 9<sup>th</sup> at 10 a.m.** **Dates to save:** October 23, November 13 & 27, December 11 & 18\* changed from 12/25

Our Generous & Wonderful Sponsors are the **Wyndham Andover Hotel, Senior Helpers** of Westford, MA, and the **Rich May Law Group**, Boston. We hope that you will support them as they support PATHS.

**Noteworthy Quote:** Trisha Torrey, a national healthcare advocate & writer recently remarked, *"Suppose you were asked to do your job faster and faster, accomplish more in a day, and get paid less for doing it.... That's what America's doctors are being forced to do, and we patients are paying the price. As a result, we need to learn to handle portions of our healthcare journeys ourselves, or suffer if we don't."*

PATHS could not agree more and that is why we created our practical 7 Steps for Navigating Your Healthcare Seminar. It is timely training that can benefit everyone, no matter their health status.

|          |               |                     |
|----------|---------------|---------------------|
| Thursday | Oct. 8, 2009  | 10:00 AM - 12:30 PM |
| Tuesday  | Oct. 20, 2009 | 7:00 PM - 9:30 PM   |
| Thursday | Nov. 5, 2009  | 7:00 PM - 9:30 PM   |
| Tuesday  | Nov. 17, 2009 | 7:00 PM - 9:30 PM   |

For more detailed information, please visit our website: [www.patientpaths.org](http://www.patientpaths.org) and go to the **Seminar** page.

**PATHS Training is mobile** – We can come to you. If you gather a group of 10 (5 patients and their 5 advocates), we will come to your site to train. To schedule a training session or just ask questions about your needs, please email [chris@PatientPATHS.org](mailto:chris@PatientPATHS.org) or call the PATHS office at 978-264-9770.

### Brunonia Barry, a Hit at 1<sup>st</sup> Edition Author Afternoon Event, held on 9/20/09

Just days before heading to Rome to receive the Baccante Award as #1 Female Fiction Writer Internationally for 2009, Brunonia Barry and her husband, Gary, spent the afternoon with 91 fans in a Benefit for PATHS. We had a lovely time as this author of The Lace Reader shared the story of how the book was created and her whirlwind trip to fame. Though a first time adult novelist, her book has received numerous awards, been translated into 28 languages, and a film script is being developed. We found her to be warm, open and it was a delightful way to spend a Sunday afternoon. We look forward to future afternoons spent in Brunonia's warm company.

We also raffled off 26 gift baskets; one guest won \$116.00 in our 50/50 raffle while another won an overnight B & B package generously donated by the Wyndham Andover Hotel.

Cornerstone Books had brisk sales as Brunonia took time to sign each and every one with a personal note. Shopping opportunities were provided by Tricia Edris and her Mary Kay team, Heidi Johnson of Partylite and Anita Shelley of Beijo Bags. It was a lovely afternoon and the delicious dessert buffet was the cherry on top.



Brunonia shared that the Lace Reading theme started with a dream and progressed to a 7-year journey

Our 4th edition of our **Meet the Author Afternoon Series** will be on the book, **Kennedy: Last Lion** and will feature Don Aucoin and his fellow writers from the Boston Globe on April 11, 2010. We will be bringing the best of New England authors to the public 3 times a year.

### Lunch with Hank Philippi Ryan, 1/10/10 Award winning Reporter & Mystery Writer

You are invited to spend a lovely Sunday afternoon with **Hank Philippi Ryan** for our **2nd Edition** in the **Meet the Author Series** on January 24, 2010.

The date to save is **Sunday, January 24, from 1p.m. to 4:30 p.m.**, Wyndham Andover Hotel, 123 Old River Rd., Andover, MA. We are changing the format from a Dessert Buffet to Lunch. Details and pricing will be available by 11/1/09. Tables of 10-12 can be reserved. Doors will open ½ hour before. For info or tickets: [author@PatientPATHS.org](mailto:author@PatientPATHS.org).

Award-winning investigative reporter Hank Philippi Ryan is currently on the air at Boston's NBC affiliate, where she's broken big stories for the past 22 years. Her stories have resulted in new laws, prison terms, homes foreclosures stopped, and millions of dollars in refunds and restitution for consumers.

Her first mysteries include:

#### Prime Time

- Winner of the prestigious Agatha
- Award for Best First Novel
- Double RITA nominee for Best First
- Book and Best Romantic Suspense
- Novel of 2007
- 2007 Reviewers' Choice Award
- Winner
- NY Times Best Seller

#### Face Time

- Book Sense Notable Book service
- NY Times Best Seller

**Just Released: Air Time** (MIRA Sept. 2009)

**Upcoming: Drive Time** (MIRA February 2010).

To learn more go to: [www.HankPhilippiRyan.com](http://www.HankPhilippiRyan.com)



Bobbie Lace Maker demonstrates her craft

## PATHS Board of Directors Welcomes 2 New Members: Lisa Honka & Carolyn DeGenova

From the President's Corner

Brian Hodder

[Brian@PatientPaths.org](mailto:Brian@PatientPaths.org).

On behalf of the entire PATHS organization I am both pleased and excited to welcome two tremendously talented, committed and energetic people to PATHS' Board of Directors - Lisa Honka and Carolyn DeGenaro.

**Lisa Honka** is employed by the Wyndham Andover Boston Hotel in Business Development and Lead Generation, and in that capacity Lisa was instrumental in two very successful fundraisers for PATHS. The events were not only successful financially, but also universally lauded by paid attendees and guests alike, which is a great foundation to build on. Lisa has been forced by circumstances to be the medical advocate for her parents so she recognizes the value of, and is committed to, supporting PATHS on its mission. Lisa has already been a great friend to PATHS, and will be a great addition to our Board.

**Carolyn DeGenaro** comes to PATHS with 23+ years of experience as a Registered Nurse, as well as professional experience in both managed health care and health care consulting. This is an important perspective to add to the Board, and complements our current range of skills and experience. Carolyn brings new energy and perspective to our Board.

We are indeed fortunate to have found two such dedicated volunteers so willing to embrace the responsibilities of the Board, and so committed to furthering PATHS towards completing its mission.

### The Question Box

#### Is PATHS' Training only for people with complicated or serious health situations?

**PATHS training is for everyone, at all stages of health.** We all are patients at some point, and the average person has several care providers in different locations that never get to meet and share their knowledge. We believe the earlier you prepare and get armed with the knowledge, the better! Here are some reasons to attend our one-session seminar, held several times per month.

##### **Reason #1- Develop a collaborative relationship with your doctor(s)**

Learn what your role in the relationship is and how you can effectively work with your doctor as a partner by logging symptoms and searching for the right diagnosis and treatment plan for you. Participants have said that what they learned could be immediately applied on Day One.

##### **Step 2- We will all be called on to advocate**

We will all be called on to advocate for a loved one at some point. We owe it to them to be as prepared and knowledgeable as possible. These are people we love. Making medical recommendations and decisions for a loved one is an awesome responsibility and you will be glad to be armed with skills and resources when you are called on to fill this critical role.

##### **Reason # 3: Resource Guide**

Each participant receives a hands-on Resource Notebook with all 7 steps outlined, suggestions on how to personalize these steps to their unique situation and many guides and resources for making medical decisions.

The Question Box: Please submit your questions by email to [info@PatientPaths.org](mailto:info@PatientPaths.org)

### PATHS News & Announcements

- Executive Director is available for speaking engagements for your club, business, or community groups. Please email her at [Chris@patientpaths.org](mailto:Chris@patientpaths.org)
- **PATHS** chosen as a Charter Member of **AdvoConnections**, a national advocacy referral service. This directory will serve patients seeking training and services. We are honored to be chosen.
- **Macy's Supports PATHS** through their **Shop for a Cause Day**. Purchase a Raffle ticket from PATHS for \$5.00. You will receive multiple discounts and you will be entered to win a \$500.00 shopping spree. One shopping spree per store will be given away on **October 17, 2009**. Contact [info@patientpaths.org](mailto:info@patientpaths.org) for your tickets, or look for us at the Acton Oktoberfest.

**Attention:** We hope you have enjoyed the 3<sup>rd</sup> issue of **Journeys**, PATHS' monthly newsletter. We pledge to never sell your name to any one. To be "green" we prefer to distribute our newsletter by email. To submit articles or comments please email: [info@patieintpaths.org](mailto:info@patieintpaths.org). If at any time you wish to unsubscribe, hit reply and type "unsubscribe" in the message line. If a friend forwarded this to you, or you receive it through your participation in a YahooGroup or similar arrangement then we can not unsubscribe you individually. Conversely, if you receive **Journeys** through your participation in a group mail service and want to be sure you will continue to receive the newsletter consistently, please use the subscribe option on our website, or send an e-mail with "Subscribe" in the subject line. Thank you.