

Journeys

Volume 2, September 2009

Could you benefit from a Medical GPS System? Then attend one of our September Seminars

Our September seminars are being offered on **Tuesday, September 15th and 29th** from 7 to 9:30 p.m. in Acton, MA. How many doctors do you currently have treating you? It is not uncommon for even a healthy person to have five or more, when you add in vision and dental providers. Are they in the same facility and do they regularly talk to each other about you, their patient? The vast majority of the time that answer is NO. Today's complicated medical systems, HIPPA (privacy law) and insurance coverage do not allow for this. Where does that leave you?

We offer low cost training twice per month in Acton, MA,. We will also come to your location for groups of 10 or more. Learn to develop a Medical GPS System for yourself. You are the HUB in your own medical care and we can teach you the tips, tools and where to find the resources to be effective and informed. Our one-session training is 2.5 hrs. and each team leaves with a notebook full of resources able to personalize our 7 steps to your unique situations. We encourage you to attend in teams of 2 with either the person that would speak for you if you could not speak for yourself or the person you would speak for. Many couples take this training together as do adult children with a parent.

Our training seminars will teach you how to put yourself on your medical team. Training Sessions are \$50.00 for you and your advocate. You and your chosen advocate will learn the following:

- advocacy and problem-solving skills
- how to evaluate your own critical and special needs
- how to choose a doctor, specialist, or hospital
- what information doctors seek that you can provide

Plus many more techniques and steps to learning how to better access medical care for you and your loved ones. We will all be called on to advocate for a loved one, at some point. We owe it to them to be effective and that takes training. For more information, visit our web site at: www.PatientPaths.org and review our Seminars page. Alternative dates are also listed and we will offer a daytime seminar option in October due to several requests. A2">A2">A2"
Option
—We come to you. Our training is completely mobile. 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 or call the PATHS office at 978-264-9770. Due to requests we are looking to add sessions during the daytime or on different days of the week. Please send your preferred dates and times to the above email address and we will try to accommodate you.

Pennies for PATHS

Please join our <u>Pennies for PATHS</u> campaign. Now most of us believe a penny is not worth much. They collect dust in our pockets, can be readily found in a sofa cushion and most of us voluntarily leave them in the change cup at the

corner store. It is not a currency that we normally value. We may remember the story of the poor widow in Mark 12: 41-44, As Jesus sat facing the offering box; he watched how the crowd was dropping their money into it. Many rich people were dropping in large amounts. Then a destitute widow came and dropped in two small copper coins, worth about a cent. He called his disciples and said to them, "Truly I tell you, this destitute widow has dropped in more than all of those who are contributing to the offering box. For all of them contributed out of their surplus, but she, in her poverty, has dropped in everything she had to live on. Her gift was only worth 1 penny but it was



all she had and she gave it with her whole heart. Her gift was precious to Jesus. Her sacrificial gift was an example and encouragement to all. She gave all she had. Jesus used an unnamed widow to teach us what giving is all about. It was less than a cent, yet was a priceless gift of love and generosity.

The lowly penny isn't valued or worth anything all by itself today. Your penny by itself my not accomplish much. But if we put your penny together with thousands of others they can perform a small miracle. We could help so many more people. So that is what we are asking for, just **Pennies for PATHS** to enable us to teach others how to navigate their medical journey, with tools, resources, and empowerment. Mail your pennies to PATHS, 116 Russet Lane, Suite 2, Boxborough, MA 01719.

"I DON'T KNOW"- A Fair Admission

By Christine S. Lang, Executive Director, PATHS

chris@PatientPaths.org

Has your doctor ever told you, "I don't know"? A recent discussion made me think more about this question. Several of the doctors were lamenting the fact that they didn't know answers for some patients, and marveled at the fact that their patients were surprised they didn't know those answers.

There are any number of reasons a doctor may not know an answer we patients need. Maybe we have unusual symptoms that require further study, or perhaps the explanation for our diagnosis is "idiopathic" -- a fancy word for "we don't know where it came from." Maybe we have a rare disease the doctor doesn't know much about. Or maybe a drug we ask about is just too new and the doctor hasn't had a chance to learn about it yet. One reply that I suggest doctors consider using to their declaration of "I don't know" with "So let's work together to figure out the answer."

Many years ago a doctor told me that medicine is still more of an art than a science. There is much that is known and even more than is not know. I found this admission comforting. Here was a doctor who still eagerly sought new knowledge, Partner with your doctor to find out the answer together, and admitted he/she did not know everything. That is the physician for me, a very human one!

Seeking Runners & Walkers for Chamber 5K Saturday, 10/3/09

The Middlesex West Chamber of Commerce Oktoberfest 5K Run/Walk will be Saturday, **Oct. 3**, 2009. Please consider representing PATHS, as a runner or walker for this 5K (3 mile) fundraiser. The race starts at the Gates School and ends on Windsor Ave. in West Acton, MA

On Friday evening, **Oct. 2**, all participants representing PATHS will be invited to a free <u>Spaghetti Dinner</u> as guests of PATHS. We will gather at St. Matthew's Church on Central Ave., Acton, MA from 6:30 to 8 p.m. to load the carbs.

Please visit the RUN FOR PATHS link at our web site,

www.PatientPATHS.org for all details and forms.

Please consider joining us for this beautiful Fall Event. We will have an education table on Windsor Ave. on race day.

Come meet Brunonia Barry, # 1 Female Fiction Writer Internationally for 2009

You are invited to spend a lovely Sunday afternoon with **Brunonia Barry**, 1st time author of **The Lace Reader.** Ms. Barry is a NY Times Best Selling author, and a native of Salem, MA, which is the setting for this suspenseful tale. Recently named #1 Fiction Writer Worldwide, she will receive her international award in Rome just days after our event.

The date to save is **Sunday, September 20th, from 2 p.m. to 4:30 p.m**, Wyndham Andover Hotel, 123 Old River Rd., Andover, MA (easy exit off I-93 and just minutes from I-495). Its central location makes it ideal.

Our delicious <u>Fall Desert Buffet</u> will feature Pumpkin Cheese Cake, Warm Apple Crisp, Cranberry Pecan Torte, Cookies, Apple Cider, coffee and tea.

For Reservations: contact Donna Wagner, author@PatientPATHS.org or 978-838-0290. Tickets are \$20.00 per person. Interest level is very high but we still have a few tickets available through 9/15/09.

This event is the 1st Edition of our_Meet the Author Afternoon Series. We will be bringing the best of New England Authors to the public 3 times a year..

Why I Volunteer at PATHS By Brian Hodder, Board of Directors President & Development Officer

It began as a simple request. A Bible Study friend asked my wife, Kim, to review her website. Kim said yes and... asked me to do it. I visited www.PatientPaths.org and it quickly became more than a casual favor.

Patient Advocacy is a topic that touches me deeply. My best friend growing up has been bed-ridden for 28 years because of a back injury that was not treated promptly, and then was treated poorly, in large part because he did not have an effective advocate. I was soon e-mailing suggestions on a fairly constant basis. The woman was Chris Lang, who decided we should meet. After three hours of sharing our life and faith journeys Chris asked me to join the Board of Directors.

I am involved because I know PATHS can make a huge difference. I often think "If I only knew then what I know now." "Monday Morning Quarterbacking" is rarely so painful. You can avoid that same gnawing feeling I know you don't want for just \$50 (for a patient-advocate team, \$30 for an individual) and just a couple hours of your time. Trust me, it is a bargain to avoid that "if only" feeling.

Almost everyone will be an advocate at some point – for an aging parent, spouse, child, sibling or beloved friend. We owe it to them to be prepared – especially when the cost of doing so is so low, and the cost of not doing so is so high.

I invite you to come join me at some level – talk to your Human Resources Department about bringing us on-site for an employee seminar, do grant research on the internet, prepare a newsletter, donate all the nickels from your deposit bottles and cans, call radio stations for Public Service Announcements, help plan a fundraiser. These last 7 months have been very rewarding and I know our services can make a huge difference in the medical journey patients must navigate. Please feel encouraged to contact me with your questions or ideas at Brian@PatientPaths.org

The Question Box-- How Can I have a Better Check up with My Doctor?

With Collaboration & Preparation---You need to understand that you have a very important role in partnering with your doctors to insure the visit has a good outcome. You are the HUB in a hub and spoke medical care system.

Step 1- Be a Detective

If you have some new systems, get out your pad and pen. Take detailed notes about what exactly is happening to how and when (what time of day, what foods you have eaten, what activities were you doing and what is your number level of pain(from 1 to 10). Taking these notes and bringing them to the appointment will help your Doctor better pinpoint exactly what is going on and get you closer to a correct diagnosis.

Step 2- Prepare a list of questions to ask

Always prepare and write down a list of questions to discuss with your Doctor before you visit. It is too easy to forget *Be Aware that physicians are under pressure to see patients in a timely, effective, and efficient manner. Take a little time, organize your thoughts, come prepared and your visit could be much more productive.

Step 3: Come to the appointment with the following:

- Pad and pen... you will likely receive recommendations and many patients forget them as soon as they leave the office. A list of your medical problems
- A list of your medications
- A list of your prior surgeries
- A copy of pertinent studies (MRI, X-ray, etc)
- A copy of pertinent medical records (valuable for second opinions).

Following these 3 simple steps will help your Doctor and you will begin to form a much better working partnership!

To receive a Doctor Visit checklist, please email your request to info@PatientPaths.org.

Providing answers to your medically related questions. Please submit questions by email to info@PatientPaths.org.

Letters to the Editor

Dear Journeys,

I read with great interest your first newsletter. Quite impressive! It seems as your organization is on the way. That is wonderful! Just a comment, please share with your readers the following tips and experiences.

The critical need to Question--Knowing your medications is important but also while you are a patient in the hospital it is most important to question the nurse about the medication that he/she is about to administer, orally, intravenously or any other way.

It is most important to question and know that you have the right to refuse until you are satisfied about the reasons for taking such medication. You are entitled to be given, the reason and purpose; not just that the doctor ordered it. You are entitled to be given the effects, and side effects. Lots of hospital mistakes can be avoided this way.

I was recently a patient in what is considered the best hospital in my area and I cannot believe the poor quality of care I received.

- I did not see a doctor for three days.
- No one came to talk to me or to examine me, or to even get a history, even to admit me
- The nurse in charge came at the beginning of the shift to introduce herself and to give me pills every 12 hours; pills that were part of standard orders but were not necessary for me, but other than that no one came.
- The nursing assistant came to take vital signs every four hours
- The emergency room doctors were competent and they were the ones who admit me. However as I get the bills, I see that the emergency room personnel is not part of the hospital, but a different organization that just happen to be housed within the hospital

I am grateful that I was healthy, all turned out to be negative and I was able to be my advocate. But it is quite scary to know that if I had been really sick and alone, I probably would have died because of lack of care.

Sincerely,

Sofia Marina Ormaza, R.N., M.S., and Cardiovascular Nurse Specialist

To submit your questions, comments or articles, email them to info@PatientPaths.org

Three Questions to Ask Your Doctor by Trisha Torry About.com Patient Empowerment

Last week I attended a conference focused on patient literacy, empowerment, and education. Among the conference attendees were doctors, researchers, educators, and advocates. The overriding theme was that most doctors aren't doing enough to help us patients understand our medical conditions, nor are they helping us make the right decisions for ourselves. The results are patients who, due to lack of understanding, just don't heal or get well the way they could or should. In extreme cases, this may lead to errors which lead to permanent harm or death – simply due to poor communication.

We're not talking about bedside manner here. We're talking about risk - the risk of patients who haven't been to medical school and need to be taught to understand their problems and treatments. As your friendly patient advocate, I was pleased to see medical professionals beginning to understand that sometimes teaching is as much their role as diagnosing and treating.

Suggestions for communications were plentiful. From developing educational materials, to making sure interpreters are available for people with poor English skills, the overriding theme was improving communication with patients, no matter what language they speak, or how well they read. It was at once eye-opening, informative, and downright scary.

One important discussion was the fact that many patients feel intimidated by doctors and freeze when it comes time to ask questions. One speaker suggested that it's impossible to ask an intelligent question of a fullyclothed doctor when we are sitting naked on an examination table, covered only with a thin sheet! We've all been there.

A simple tool was discussed that is worth sharing with you. It's called "Ask Me 3" and it's a series of three questions you should always use when you visit your doctor for a medical problem.

Question one is simply, "what is my main problem?" It gets to the heart of your diagnosis and helps you understand what you've got.

Question two is: "What do I need to do about it?" Your doctor's response will outline your treatment options and prepare you to learn more about them.

Question three is: "Why do I need to do that?" This will help break down each treatment option into its benefits and components and will help you make the treatment decision that works best for you. www.diagknowsis.org/

Many Doors are opening to PATHS

News & Announcements

- Executive Director is available for speaking engagements. Please email her at Chris@patientpaths.org
- Corporate Training Available- We are being contacted by companies to come in and teach our seminar at their site. We have found creative ways to accommodate these requests. Perhaps your company would like us to train at your site. We can be flexible and creative, for more information, email info@PatientPaths.org
 - Flatbread Company- thank you to the people at Flatbread Company in Bedford for opening their doors to PATHS on Tuesday evening, September 1st. We raised \$349.25 from patrons who simply bought a small or large pizza. Our 50/50 raffle winner was Mary Jane McInnis of Bedford, congratulations. We have been invited to make this an annual event. Their pizza is deliciously hand tossed and baked in a very special domed brick oven; we hope to see you there next time.
 - Volunteers Still Sought- many are coming forward and we have many fun and creative opportunities. Please visit our web site to see our current lists of needs. We offer a lot of flexibility on time and task, and most can be done from your home.
- We continue to meet with area churches and medical groups inviting them to come along side PATHS and share in our work. We are getting positive reactions and are pursuing these working relationships. We have met with the Elders of Mt. Calvary Lutheran Church and the Pastor & Parish Nurse at St. Matthew's Methodist Church, both in Acton, MA. We appreciate their interest and prayers for our work and have enjoyed our meetings and discussions.

Attention: We hope you have enjoyed the 2nd issue of Journeys, PATHS monthly newsletter. We pledge to <u>never</u> sell your name to any one. To submit articles or comments please email: info@patieintpaths.org. If at any time you wish to unsubscribe, hit reply and type "unsubscribe" in the message line. Thank you!