YOUR SAVVY PHARMACIST

Before big store pharmacies took hold, the corner drug store was a convivial place. In the old days the drug stores even had soda fountains where you could get a hot fudge sundae, but I’m showing my age now. Life has changed considerably and it is unusual to find a pharmacy with a long history of ownership as with the Block Drug Stores that opened in 1885 and proudly claims to be the second oldest pharmacy in New York City. The Group was indeed fortunate to have as its guest lecturer Carmine Palermo, Pharmacist, owner and director of Block Drug Store. Mr. Palermo regards the position of pharmacist to be a serious responsibility to the community he serves. He provides support and education to his many customers.

Palermo stressed the need to be in charge of your own temple with regard to your medical condition—which the more you learn about your particular disease the better you are able to cope with associated problems including side effects. By playing a part in your own health you demystify your disease and move into the role of partnering with your pharmacist and the medical staff involved in your care. While your doctor may concentrate on the medical aspects of your disease, time and circumstance often mitigate against the doctor’s spending much time educating you. Furthermore, you are responsible for the most part in navigating the insurance companies’ protocols. Chances are that if you are internet literate, you will take a look on the web to find out more about your disease, but, all too often, the information is sketchy and may not be current. Fortunately, for our Group the information we provide with the newsletters and guest speakers help to fill this gap. In Palermo mentioned several sources of information other than the Internet. One valuable reference guide is the Physicians Desk Reference Guide. It is revised every 8 to 10 years and can be purchased on the Web for less than ten dollars. A second source of information is the insert that comes with your medication. The pharmaceutical manufacturers...
include an analysis of the drug’s components along with side effects and temperature parameters. You may need to use a magnifier to read the small print. Not all information is included in these inserts, however. Palermo cited the reason for this omission is that the drug companies believe that by leaving out certain pieces of information, they may avoid future lawsuits, and in our litigious society, the drug manufacturers don’t want to create more problems for themselves. Palermo assured the Group, however, that the insert information, once quite technical, has become more user-friendly.

What effect does eye medication have on our body? Although the majority of us occlude religiously some medication does enter the system, less topically than orally, but, nevertheless, requiring metabolization by the body. This means that in rare cases, although the amount entering the body minute, it may still have an effect, especially with such medications as the beta blockers.

Instilling eye drops for some people may be a problem especially when they are unfamiliar with the anatomy of the eye, for the eye can only hold one drop – that’s it. Some people are so unsure about putting their drops in that they put several drops in the mistaken belief that more is better. This practice will lead to using up the drops before the next order can be delivered. Palermo has found that some people may use up a 5-milliliter bottle in 10 days. Fortunately he explains patiently that only one drop be used at one time and advises the patient to get a helper if instilling a drop presents a problem. Drops that are not generic are generally costly and overuse of drops can pinch the pocketbook. To the eyedrop, pull down the lower lid to form a pocket, instill drop and then place your finger on the tear duct located at the inner side of the nose. Feel around until you feel a small bump. Keep finger there for about 2-3 minutes.

Alphagan is similar to Visine and one of the effects is to reduce the redness of the eye. Visine is generally not recommended for glaucoma patients for it constricts the blood vessels. Palermo feels that Visine can be used for a specific problem for a few days until the particular problem is resolved, but not on a long term basis. If your doctor recommends Alphagan, however, it is for a particular condition.

Blood flow to the eye is an important issue for glaucoma
patients, especially those with low-tension glaucoma. Many pharmaceutical products affect the blood flow to the eye such as those used for diabetes, uncontrolled hypertension, and cardiac drugs.

The prostaglandins are now the medication of choice for newly diagnosed glaucoma patients. Its once-a-day schedule is attractive especially since it is instilled at nighttime, making it easier to remember. Once considered a medication with minor side effects, that of pigmentation in the iris of light-eyed people and abnormal growth of eyelashes (welcomed by women), it has been discovered that it is not so benign after all. The prostaglandin family (Xalatan, Travatan, Lumigan) also cause the eye to become deepset creating both a cosmetic problem and a challenge to doctors performing surgical intervention in the eye.

GENERICS: Within 17 years or so medications can go generic. While the generic manufacturer uses the original formula, they company may make minor changes of which the patient is unaware. For example, the FDA states that 85% of the original formula must be in the generic version. Sometimes that 15% makes a big difference in managing the disease. Another problem is the site of manufacturing. China and India produce many of the generic medications and it is difficult to determine whether or not they have made short cuts in a drug’s manufacture. Palermo recommends Greenstone, owned by Pfizer as a trusted brand. There are different grades of generics. Block Drug keeps a record of A-B rated medications. The medications they sell must possess 95% of the formula, but not all sources for medication sell the A-rated. The FDA is responsible for testing a drug to ascertain that it meets the required standard. There may be times, however, when a drug company finds a way to disarm the FDA. In 1980 there was a scam where a company bought brand name drugs and filled their own capsules, passing them off as their brand and then sending the capsules to the FDA for approval. Apparently more than one generic company did that and when the FDA discovered the scam shut down some 60 generic drug companies. Although there is a tighter lid on generics, a pharmacist can legally produce and sell a product with only 80% of the formula. Palermo feels that
such a drug would probably not be effective. This problem exists particularly according to Palermo with mail order pharmacies that are not monitored. The mail order pharmacies have penalized patients if they do not use their services, but apparently this is no longer the case, for Governor Cuomo signed a bill stating that mandatory mail order was no longer acceptable in New York, except (and this is a big exception) for city, state, or local government employees. The UFT, the United Federation of Teachers fought the mail order requirement, relieving retirees of mandatory mail order, but the companies still put up a fight. One patient had to put in a special request from her ophthalmologist before a brand drug could be approved. You do need an override to get a brand name from your doctor.

In certain instances, your local pharmacist may be competitive with a mail order pharmacy. If you are not required to do mail order, why not ask if your pharmacist can match the mail order price. This holds for generics basically, for a brand generally will be much higher than the mail order.

MEDICATION MATH: This is how it works. 1 milliliter equals 20 drops. A 5-milliliter bottle contains 100 drops. That bottle is supposed to last for 50 days, not a full two-month supply. This is true of Xalatan.

A 2.5 milliliter bottle taken four times a day is a 25-day supply. The insurance companies have just implemented this standard into their system, and they are very tight. This means, of course, that the bottle is not designed for a month—30-31 days. Of course, the drug company profits the 25-day protocol.

Not all drug companies are this parsimonious. Cosopt lasts longer than 30 days and you can still receive a bottle every month. Furthermore, some bottle tips emit more than one drop thus using up the medication before the allotted 25 instillations. Those of us who are retired and/or on Medicare, differences in the amount of medication available on a monthly basis may be problematic. There are gadgets that emit only one drop and can be found in mail order catalogs and on the web.

Note: There is a lawyer who is setting up a case to sue the pharmaceutical companies for the size of the drop nozzle. He’s working in two states. If this case is heard and won the
pharmaceutical companies will have to redevelop their bottles according to a one-drop at a time standard. This attorney’s research showed that some years back the bottle tips did emit one drop, but the pharmaceutical companies remanufactured the bottles, making the opening larger.

REFRIGERATION OF DROPS: Palermo stated that they receive Xalatan in a refrigerated box. The medication can be outside for 7 days without refrigeration before it is opened. According to the company the drop once opened can be used for a thirty-day period – one month. Some people use just one drop in one eye and obviously, the medication will last beyond the 25-day period, and it is tempting to keep using the drop until finished. Palermo suggests that drops be used only for the 25 or 30 thirty days for which they have been designed. Subtle changes occur in the drops after that period and the drops will not be as beneficial in controlling pressure.

Refrigerating Xalatan while maintaining its strength makes it cold to use and some people complain about eye irritation as a result. Xalatan, therefore, stated that it could be outside for the 25 days, but it must be disposed of at the end of six weeks. Both Lumigan and Travatan do not need to be refrigerated. Keeping eye medications around for a long time is not a good idea for the antibacterial and antifungal chemicals protecting the medication become useless after a 30-day period and protection against infection becomes, therefore, impossible even when constantly refrigerated.

TEMPERATURE CONTROLS: Generally, room temperature is fine with most medications, but a hot un-air-conditioned room in the summer may post a problem. Check your insert for temperature parameters. As an example, Travatan can be stored between 36 and 77 degrees. Xalatan 36 to 46. Upon opening, it may be stored up to 77 degrees for up to 6 weeks. Alphagan from 59 to 77 degrees. In the summer time keep the medication in a cool drawer. Cosopt is room temperature.

If you add a product to your eye and you start to get blurriness and it continues, check with your doctor. If one medication in a family, caused blurriness, and a second does also, probably a third in the same family will follow suit. The bottom line, of course, is did
the medication reduce your pressure sufficiently? Another question to ask yourself – is the blurriness temporary? If so, and the medication is effective, can you tolerate a short period of blurriness? Such questions obviously suggest a discussion with your doctor.

Palermo suggests that when you have questions about your medication check them out with your doctor and if the doctor doesn’t have the time to explore other meds, then ask for a second opinion.

Alternatively, you might investigate with a pharmacological doctor who is trained to review your medication and might be able to act as your advocate. In some cases you may need an advocate.

Some of the older drugs such as Pilocarpine and those in the atropine family can cause blurriness. But you will be informed when your eye is dilated with an atropine that blurriness will occur for a period of time.

Photophobia produces another problem that you should not have to tolerate—light irritating your eyes. You might get a migraine when you walk into a room that’s too bright. Glaucoma patients often complain of the effects of bright sunlight reducing contrast. Under these circumstances it is wise to see a low-vision specialist who can recommend a filter to ease the problem.

The beta blockers (Timoptic, Timolol, Betagan) are well absorbed into the body. There are conditions with the beta blockers that are very important. Betagan was very strongly advertised as being less apt to cause reaction but Palermo has noticed that this medication is also questionable. Timolol, however, is a very strong beta blocker. Problems may occur with people using the beta blockers and who are on medications for other physical problems such as asthma, blood pressure and procardia (swelling of the heart). COPD (Chronic pulmonary disease) is a serious illness where the beta blockers tend to slow down your breathing and aggravate the condition. Palermo cites a case of a patient on Timolol drops who said that he was being monitored. The beta blocker was dispensed with the knowledge that his physician had prescribed it, but about two weeks later, the patient had to be switched to another medication for Timolol aggravated his asthma. Now he needs to use his oxygen more often.
Doctors often walk a fine line with patients who have several medical conditions, for they attempt to use the ideal medication to keep the disease at a steady state where it keeps the condition stable. But when two unrelated diseases are being treated, it is wise to have your ophthalmologist speak with your internist to solve the problem. Sometimes, adding another medication may cause a problem. For example, Prednisone can aggravate and cause secondary glaucoma and can aggravate other conditions of the eye.

Blood pressure medications may not cause a reaction except that lowering the blood pressure too much may cause reduced blood flow to the eye. Sometimes a person’s blood pressure needs to be lowered considerably to control the disease state. Ideal blood pressure now is 120/80. By lowering high blood pressure, the process can lower the blood supply to the eye. It may not necessarily cause glaucoma but it may cause other problems like ocular elevation of pressure. Reduced blood flow to the eye may also worsen the glaucoma condition.

The two related organs in the body are the eye and the kidney. It is possible to diagnose a kidney disease by looking into a person’s eye. This method was used in the 60’s and 70’s. They did find there was an association with kidney problems and eye problems.

Narrow-angle glaucoma and prescription and Over-the-Counter Medications. Drugs that cause dilation of the eye are a problem because they expand the iris so that it blocks the outflow channels. There are other interactions that may also occur but most of these are rare. However, if you notice something that doesn’t seem right, contact your doctor. Some drops do cause dryness that then often requires another drop (usually over-the-counter) to counteract the dryness.

Any drug you take is metabolized either by the kidney or the liver but mainly by the liver. If you have sclerosis of the liver, consult with your physician as to whether to use this particular drug.

PRE-POST OPERATIVE MEDICATIONS.

Many times these meds will be added on as non-steroidals. A non-steroidal medication is similar to Advil, Alleve, aspirin -- all of which may cause an ulcer, or if you have an ulcerous
condition, stimulate it. Non-steroidal medications such as the NSAIDS will relieve pain following an operation. Prescription drugs that do the same thing include Nervanic, Ocutaine, Quataren, Nocuof. These drugs are anti-inflammatory. They reduce the swelling that’s a product of the operation while also alleviating pain. The only side effect found with these drugs is that cure time takes longer. They also thin the blood and, therefore, may cause a little bleeding. But that’s acceptable. They may be used together with Prednisone, which is also a non-steroidal. Palermo believes that two non-steroidals can cause some more trouble especially if used on a long-term basis. The drugs are basically designed to be used for a short period to curb inflammation. With Prednisone it is necessary to gradually come off the drug.

On the other hand prolonged use of steroids can cause glaucoma with damage to the optic nerve and can affect visual acuity. In some cases, for example, a patient needs to be on Pred Forte to control another condition and runs the risk of developing glaucoma.

People who have Crohn’s Disease, asthmatics and COPD diseases are all treated with steroids and Prednisone is contraindicated in these cases. Unfortunately, thousands of children are prescribed Prednisone, and, unfortunately, many diseases develop from that use. Temporary use usually does not cause problems but long-term use may.

Redness of the eye doesn’t necessarily mean damage. It means that your outer coating, the sclera, is inflamed. Redness is an adverse reaction to being irritated. Your doctor can usually prescribe another medication that does not have this effect.

Dry mouth may also be a side effect of the eye drops. Basically many of the medications do not cure but eliminate or tame the effects of the disease or in some cases, the side effects of another medication. Ideally the body given some assistance will cure itself. After a procedure, the medication you receive is for a short period of time to help the alleviate pain and the inflammation. This does not hasten the healing but makes you feel more comfortable.

A good example is ProbideX used for inflammation with associated bacteria. It also possesses a steroid to alleviate all symptoms. The antibiotic will
work but will take a few days but some people are too antsy to wait those few days and prefer to go with a medication that works more quickly but which may have negative side effects.

Medications a glaucoma patient should not take fall into the class of antihistamines, but usually for narrow-angle glaucoma as indicated previously. Compazine in general is contraindicated for glaucoma patients; codeine is another. One or two days may not cause a problem, however. It’s an antiemetic and is used to stop vomiting, especially if you’re diabetic. The older antidepressants are also not good for glaucoma patients. The key to any medication is careful monitoring.

The sleeping pill Dalmane can be used with no problems. It’s also an anti-anxiety pill.

Before you ever use an off-label product, try to exhaust the avenue of approved medications.

We want to thank Mr. Palermo for the wealth of information he provided relating to the drugs we take and how they may affect eyes with glaucoma conditions. We learned a lot from his lecture. The Block Drug Store is located at: 6th Street & Second Avenue 212-473-1587.

WARNING TO SWIMMERS -- swimming with goggles raises eye pressure. We wear the goggles so that we don’t get chlorine in our eyes. Study shows a pressure rise from the teens to into the 40’s within a few minutes. That’s pretty scary. The pressure goes down after you take the goggles off but a pressure spike like this is not good.

DOCTOR/PATIENT RELATIONSHIPS
Moderator: Edith S Marks
Part I
February 16, 2013

In our lifetime we form many relationships, some intimate as with our partners and our children, some sharing as with friends, others distant but necessary as with our health professionals, a relationship that can be a life or death issue, but is more often a healing relationship. Many of our illnesses are short term, but some as with glaucoma, a chronic illness, require a lifetime relationship in order to preserve our vision. And therein, is the problem. Both doctors and
patients need to exchange important information, the doctor on the state of the condition, the patient to report accurately the effects of the treatment.

Sharing information is an important aspect of treatment. The doctor is not clairvoyant and the better the patient is able to observe and relate observations and health issues helps the doctor to steer the course of treatment. The doctor-patient relationship is beginning to shift away from a one-sided affair, as both patients become more knowledgeable about their conditions and younger doctors invite patient participation. In fact, some doctors now openly advocate it as expressed in a recent article by two Emergency Room doctors at Brigham Women’s Hospital in Boston, Massachusetts. They observed that it really is up to the patient to tell the doctor what’s going on. Saying you have a pain, for example, does not provide much information. If you tell your doctor, however, the circumstances surrounding the pain, when you became aware of it, how often it occurs, and other pertinent information relating to it, the doctor may be better able to diagnose your condition.

Many doctors are now using a more patient informational approach. Recently I had that kind of experience. I was referred to a specialist. At my appointment I was not subjected to a series of tests before I saw the doctor, rather the doctor asked me to tell him the circumstance of my symptoms. I spoke for about fifteen minutes and only then did the doctor order tests. I will return to this doctor. On the other hand my former GP could no longer practice and I found a new GP who immediately ordered a series of tests, which I didn’t take. Challenged, he advised me he could not treat me since I obviously disobeyed him. Subsequently, I found another GP who listened and respected my decisions. Incidentally, research recently revealed that patients didn’t need the evaluative tests I had turned down provided the patients were symptom free.

Another problem the ER doctors discussed was exactly the above situation. A doctor hands you a list of tests and you have no idea why you need them. Does the doctor suspect a malevolent condition? Some of these assessments are invasive. Why does your the doctor recommend them?

Alternatively, you may be too nice to say anything and simply obey like a good patient. Some alert physicians have noticed how
nice their patients are. We’re nice, really nice. We don’t want to hurt our doctor’s feelings. A doctor will say something, and we’ll accept it, even though we have misgivings about undergoing this or that procedure but we don’t want to challenge the doctor. I knew a remarkable dentist at one time who said to me, “You know your own body.” She was right, of course. In the end we are the arbiters of our bodies. We live in our bodies and oh, do we know it. So, if you think something won’t work for you and you’re too nice to demur, you may doing both yourself and your doctor a disservice.

Learning the terminology is a step forward in the doctor-patient relationship. The doctor will say, you need a trabeculectomy, or you need an operation. An operation today could be any number of procedures. It can be a shunt, a trabeculectomy, cananoplasty, laser procedure and so on – they’re all operations. You need to know what is suggested or is going to be done. If the doctor says, I think we’ll do an eye stent. What the hell is an eye stent? You have no idea. But again you’re too nice to ask what an eye stent is, and how it is performed, and what you need to do following the procedure. Despite these issues, most of us respect and appreciate our doctors for if we do not feel comfortable with our doctors, we very often seek another doctor.

At times, however, your doctor may suggest that a specialist be consulted, or you may ask to be seen by a specialist. Now this highly qualified doctor takes a quick look and as quickly announces we’ll do this, this, and this. You don’t understand what you are being told and, furthermore, it all sounds frightening. And maybe you don’t want any further intervention. You never return to that doctor although some of the recommendations might have helped. On the other hand, and here we return to being nice again, you may not want to hurt the feelings of the doctor that you really like and may not seek out other treatments that may be beneficial.

I read about a woman with Stage 4 breast cancer. She was told that at best she’d live 5 years. She talked with her oncologist, and decided she didn’t want chemo and radiation with its associated ill effects. She was not unduly suffering and she preferred to go as long as she could in her present state, but her oncologist suggested making an appointment with a well-known
specialist, tops for her condition. Being a “nice” person she went to see him and he proposed the chemo, radiation, the whole works. He said, “That’s the protocol for all my patients.” She said, “I don’t want radiation. I’m living a decent life.” She stood her ground and again refused the standard protocol.

MEMBERS OF THE GROUP SPEAK UP.

I think doctor/patient relationships should be good. I’ve had some issues with doctors; specifically they wouldn’t let me alone. This was a gynecological issue, a D&C, but the doctor said that I needed a hysterectomy telling me that she wouldn’t put me through a D and C. Someone else told me to go to another doctor, the chief of staff. And although I was not happy with him, he performed the D&C. (Editor’s note – doctors perform more hysterectomies in this country than any other country in the world).

PUSHING THE ENVELOPE: With internet and television, some of us become overnight experts in our conditions. We take information we have gathered to our doctor. We glibly toss out medical terms. There was a wonderful cartoon in The New Yorker. A big sign on the doctor’s wall read: PLEASE DO NOT MENTION DR. OZ. We arrive with these bits of information, smug in the knowledge that we have become an informed patient and we present our findings to the doctor expecting praise for our efforts. Chances are your doctor will ignore your efforts as a threat even though you may not mean it that way. This doctor may be very effective in treating your condition. So do you drop your attempt to interact on another level or do you revert to an old-fashion doctor-patient role? There is no standard answer to these questions, but they do require thought.

Another problem may arise when you find yourself dithering about having a procedure. Is it because you don’t understand exactly what is involved and your questions may be simply answered if you just ask them. You may want to know when you can go back to work, what steps do you need to take while the eye is healing, why you need to take so many drops before and after the operation, if certain foods of liquids will affect the healing process, what exercise level. If you have trouble remembering
what you need to ask, write them out and hand them to your doctor.

Not too long ago I fractured my ankle. Immobilizing a fracture limb no longer requires it being encased in a plaster cast. Instead a plastic brace is attached with a Velcro fastener. As the medical assistant brought out the plastic brace I reached for my sock. He shook his head and affixed the plastic brace to my bare skin. I was doubtful but didn’t insist on the sock. Within a day I experienced severe contact dermatitis. When I told the orthopedist he said I should never use plastic directly on the skin. I didn’t insist forcefully enough with the assistant.

Several people discussed problems associated with surgery such as the operation failing immediately or within a month or more. One member said she was a total medical wreck. In addition to the affected eye, she found other problems occurring that she attributed to fear.

Another member who had been a caseworker empathized both with the doctor and the patient, for in her work she experienced the trauma of being involved in such cases. As a result she had to leave her job because of burn-out.

It is frightening not to do a procedure. And then after the procedure to be told that it didn’t work out right and the procedure needs to be redone. The doctors are trained not to be involved in your emotional responses for if the doctor loses his/her objectivity, s/he may lose perspective. It’s a necessary defense to prevent burn-out.

SECOND OPINIONS: One doctor advised his patient to go to Philadelphia for a second evaluation. She considered that a sign of a good doctor. Medicare will pay for one second opinion but in most cases not for a third and fourth. You won’t hurt your doctor’s feelings if you ask for a second opinion.

If your doctor doesn’t suggest a second opinion, you are within your rights to suggest one. A number of people choose Dr. Quigley at Johns Hopkins in Baltimore for a second opinion. One of the members found it was less expensive even including the transportation and an overnight hotel than having a second opinion with some doctors in New York.

CHOOSING A DOCTOR: Perhaps the problem lies in the initial choice of doctor. What is the criterion for choice? On what
basis do we decide to choose a
doctor to treat our condition?
There is a very good site on the
Internet. It’s a NYS Physician
profile that lists every physician
who practices in New York. It
provides information about
malpractice suits, education and
also where the doctor practices
and other pertinent information.
While it may be difficult to choose
a doctor based on cold facts, this
site can be quite helpful in
making a choice. One of the
members detailed how she went
about choosing a doctor. She said
she would rule out some doctors
advanced in years for since her
condition is chronic, she knows
she will be with that doctor for
the long haul. Younger doctors
who had already built up a
background of experience might
be a better choice for they would
probably be more adept in the
new technologies and familiar
with recent research findings.

One member appreciated
that some doctors presented the
facts including the pro’s and con’s
and as a result she became
comfortable with the doctor. If a
doctor knows his expertise and
knows how to present needed
information, the patient feels
comfortable both with the doctor
and the procedures offered.

Another member reported
that when she was first notified
that she had glaucoma, she made
an appointment with somebody
known as a doctor’s doctor, a
glaucoma specialist. He was
efficient. He told her she would
need surgery, but she needed
some questions answered such as
how long she’d be out of work, the
recovery time, the protocols she’d
need to take. He was busy at the
time so she called several times to
see if there was a time when she
could speak with him or possibly
speak to an assistant. The idea of
having surgery was frightening.
But neither he nor anyone in his
office responded. So she wrote
him a letter telling him of her
experience with his office and
that she probably was not the
only patient that had this
experience. She also stated that
she would no longer be his
patient, that she had found
another glaucoma specialist.
That’s what you have to do. Let
doctors know that the patient
needs to be treated with common
courtesy and respect. This
member believes that it’s good to
either confront the doctor or
write a letter to advise the doctor
and his staff the effect they have
on patients when the patient’s
requests for information are
ignored. Subsequently this
member did receive a phone call but by this time she had found another doctor. She learned later that her letter was effective in improving the procedures in his office.

One of the long-time members of the support group stated that she accepts her glaucoma so that the rest of her body doesn’t get ill from it. But she will fight it to her last breath. She has visited doctors who have told her that she has so little vision in one eye she does not need to take drops. But she is determined to save what she has. She wants to know everything the doctor knows about her condition. She urges patients to ask doctors what their pressures are. They have a right to know as they have a right to know the form of glaucoma they have. Patients need to take on a more activist role. The outside world will not advocate at the same level as the patient experiencing the prospect of potential blindness.

One patient described standing her ground when the doctor advised retinal surgery that required her head to be kept down for a period of time. She refused that surgery knowing that position might compromise her glaucoma.

QUESTIONS: We all have questions but they seem to vanish when we are with our doctor. Write out your questions. Bring them with you or send them to your doctor in advance. That way your doctor will be prepared to respond and allay your fears. Often, we worry needlessly because we lack information.

Alexander Pope, an 18th century English poet wrote “A little knowledge is a dangerous thing.” Of course it’s true as many of you have found, but in certain cases, a bit of information can help you shape an appropriate question. When a doctor says I see changes, ask what do those changes signify? The visual field is an excellent instrument for measuring vision loss, but perhaps, you and the test are not compatible or you hadn’t slept the previous night or a disaster had occurred in your family. You have a right to retake the test. If for some reason you cannot take the test you can ask your doctor to do a non-invasive test such as the Heidelberg or the OCT. Both are electronic devices that measure the nerve fiber layer and provide an accurate reading of vision loss. Teaching hospitals have these instruments.

Sometimes when you do a visual field, it comes back saying
too many errors. One of the problems when first taking the test is that the medical assistant doesn’t explain the procedure carefully enough or doesn’t monitor you while doing the test. For example, if you tire, you can hold down the button and give yourself a little break. Another problem may be the distraction of people chatting within earshot. Not only do you have to speak up to your doctor but to the medical assistants or technicians as well.

A member reported on a recent experience that put the visual field test in perspective. She felt she was losing vision but two visual fields did not corroborate her impression. Her doctor told her that the visual field tests only the acuity range of vision, but not contrast sensitivity, and color perception. She learned there were four components that comprise vision and then she realized that a different component had deteriorated, one not tested by the instrument. With that knowledge, her anxiety about taking the test lessened.

One member stated she schedules visual fields early in the day, after taking her drops believing that her eyes are in the best shape at that time. Another member added that it is helpful for the physician to use an Amsler grid. It’s a quick way of indicating vision loss, and incidentally, legal blindness.

**SELF TESTING:** A member stated that she puts one hand over one side of her face to check each eye’s peripheral range.

Lovett added that people find by self-testing that they can still do this or that.

### PART 2
**ADVOCACY/AWARENESS**

Joe Lovett, producer of the documentary GOING BLIND, joined the Group. He has been showing the documentary worldwide to raise awareness of glaucoma. He brought a special message to the Group – Advocacy. While we do at this stage accept inevitable vision loss, we cannot be passive about it. We need to demand more research. Lovett began his medical reporting at 20/20 with the AIDS epidemic where young patients did not accept the death sentence of this illness. They hammered the government and the doctors until research for effective medications was developed.

Lovett announced that there would be a state house screening
of Going Blind at the State House in Albany on April 30th at 5pm. He invited glaucoma patients to come. Before the screening, people can meet with their representatives to discuss the issues facing those who are blind or have low vision. Legislators need to know that there is a community of people afflicted with this debilitating condition and who care about these issues and are displeased with the dearth of interest and support.

Lovett also announced that he was in touch with Dr. Ritch and reported that Dr. Ritch aggressively pursues possible cures or remediation of glaucoma problems. Dr. Ritch supports an active research team. As well he is in close touch with the best in the field. Lovett feels there’s a disconnect between treatment and quality of life in ophthalmology. The problems associated with vision loss seldom enter into the treatment plan. How often has a doctor asked you, “just what are you seeing?”

Lovett addressed the medication issues. Drops have been the first standard of treatment for a long time. Some professionals refer to glaucoma as a benign disease implying all that needs to be done is to keep the pressure in check through the various procedures of medication and operations. At conferences, however, glaucoma is referred to as a relentless disease.

Lovett advocated for more basic research into glaucoma especially since it is now increasingly evident with brain research science that there is a connection in the neural pathways with such diseases as Alzheimer’s, MS, autism and possibly other behavioral diseases.

But there are some treatments not approved by FDA that exist in other countries and these might benefit us. He mentioned a form of treatment in Germany that acts on nerve cells and establishes new connections in the brain to stimulate better processing of the object viewed. The treatment is called alternating current stimulation. The laboratory is a two-hour train ride from Berlin to the University of Magebourg. It is directed by Dr. Bernard Sabel. Lovett speculated that if the theory works, perhaps the protocols could be extended to the other brain diseases mentioned above.

He has seen results of the therapy. When he began the therapy, he couldn’t see his left pupil with his left eye when he looked in the mirror. After the
therapy, he was able to do so. He also attended a ballet in Berlin and was able to read the program with his left eye with and without his glasses. Normally he couldn’t read with his left eye very well at all. And, adding to his enjoyment, he could see the details of the dancers’ faces on the stage.

The improvement diminishes over time, but it appears to improve the sight in the long run. The treatment regimen requires daily treatments for 10 days at six-month intervals. It is designed for optic nerve damage and is used for glaucoma, trauma, stroke and tumor. There’s a little video on UTube about it. [http://bit.ly/ZGRO7W](http://bit.ly/ZGRO7W).

Lovett also stressed that as a group or as individuals we can have an impact on the FDA. We needn’t sit around waiting for something to happen but can lobby the FDA to make a move. It is within our right to make an appointment and be heard. We can go as a delegation.

Lovett cites an all too familiar story about receiving a phone call from a 67-year-old man who went in for a routine contact lens exam in upstate New York and discovered that he has tunnel vision. His visual fields showed profound vision loss, but the doctor had told him that he had moderate glaucoma and given him drops and set up a follow-up appointment in a few months. The man went on the web, found information and also Lovett’s film and expressed his dissatisfaction with the information available. Lovett referred him to a glaucoma specialist in New York City who, of course, diagnosed very severe loss.

Another man who has had glaucoma for 35 years, and has lost a great deal of sight visited the Lighthouse for help in best dealing with his situation was advised to call Lovett. There is a disconnect here that needs to be addressed. When the pre-eminent place for Vision Rehab the Lighthouse refers the patient to a documentary filmmaker rather than more help at the facility, something is wrong.

Further in this man’s travails a doctor at The New York Eye and Ear also suggested calling Joe Lovett. (Editors Note: I receive these so called “referral” calls on an ongoing basis. GSEG has repeatedly asked doctors to refer patients to members of our Group for assistance since our Group has become a reliable source of available resources for information and support).
But Lovett rightly suggests there’s something wrong when available information is not readily shared on the web sites of organizations involved in the disease.

Another problem that surfaced at least thirty years ago is the need to add a clause or establish a new category in addition to the definition of legal blindness addressing low vision. Until the legislation is passed, the insurance companies including Medicare will not reimburse for low-vision therapeutic devices.

Perhaps if we address vision loss rather than generalized glaucoma, the people suffering from these conditions would likely be more activated to pursue research and activation. People with other eye conditions also suffer severe vision loss and need accommodation.

Lovett believes that part of the problem is fear of blindness. Actually this non-sharing of information with the patient is prevalent throughout the health field. It’s only with the advent of the Internet where patients can research facts about their own diseases have doctors become more forthcoming about the nature and prognosis of the illness. Perhaps because of our terror of blindness, we avoid the subject. Since a small percentage of glaucoma patients develop serious vision loss, to find out more does not become an issue. Lovett posited that this reluctance to face blindness may lie with a prevailing prejudice against the blind and that we may inadvertently incorporate this prejudice, feeling “less than whole” and embarrassed or ashamed by our visual inadequacies.

Losing vision produces anxiety, possibly depression and despondency, and we may just retreat. Where there is a strong advocacy group for a disease, more support both governmental and community exists. At the World Ophthalmology Conference in Berlin in June 2010, an individual approached Lovett and suggested an experimental treatment asking if Lovett was interested. Lovett, of course, wanted to know more. And this is how he found out about the treatment In Germany.

The various glaucoma foundations are now directing their resources to research and provide little room for support systems for patients.

There’s strength in numbers and we need to bring the baby boomers into the fray. Glaucoma knows no bound-aries and there
is a need to work with the World Glaucoma Support Organization. January was Glaucoma Awareness Month. More publicity is needed.

We want to thank Joe Lovett for reviving awareness of the need for patient self-advocacy. This has also been one of the missions of the GSEG. One of the long-time glaucoma patients now blind from the disease began work on legislation issues many years ago. Despite her blindness she is still working on the issue. Her analysis of the situation lies in the fact that the doctors are no longer required to fill out a form reporting legal blindness. It is up to the patient to request that the doctor’s office submit the paperwork to the NY Commission of the Blind in order to receive services. She is working at this level. The second level and this is much more difficult is legislation that includes low-vision as a handicapping condition to make this condition legally entitled to services. This legislation requires a bill to be prepared by our congressional and senatorial representatives and presented to Congress for a vote. Such a bill requires lobbying a particular congressperson to this effect.

On a grassroots level screening for glaucoma needs to be revitalized. With the portable visual field instrument it is possible to screen a large number of people within a given period of time. About six or seven years ago, this kind of screening was conducted by a number of “vision” agencies. This level of screenings has dropped considerably.

Lovett suggests going directly to the State House with a NY delegation. He has spoken with Carl Jacobsen, president of the National Federation of the Blind, New York chapter, who expressed an interest. This is an important issue. Blind people have representation. They were one of the first disabling conditions to receive services, but people losing vision tend not to have a voice. Legislators need to realize that loss of vision does not equate total blindness but is a serious handicapping condition. Most people with vision loss fall somewhere along the spectrum between sighted and non-sighted. This is a difficult concept for others to understand, but it is our job to raise awareness.

OTHER INFORMATION: Citicoline is a form of B vitamin that has shown positive results to retain nerve function. It can be purchased over the counter.
Lovett Website:  
www.goingblindmovie.com  
Also they are on Facebook.  
Please note:  We began our workshop speaking about doctor-patient relationships but it morphed into a call for creating public awareness of the disease. This is a good thing, for in the course of this workshop, we discovered with the aid of Joe Lovett that while we depend upon our doctors for medical care to receive the services and support we need, it is up to us to become advocates for glaucoma awareness and general support.  
Edith S Marks, Moderator

Please note: The contents of this newsletter are for informational purposes only. The Content is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.

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