Bronx Health REACH News

Fall 2007

A Letter from Our Project Director

Dear Readers,

Too often we find ourselves being cared for by doctors who seem too busy to listen to us. Often they don't take the time to explain our ailments and the treatment we need. Other times they use language that we don't understand. Too often we feel frustrated and powerless when we wait too long to see a doctor or when we receive care that seems less than what we need. In this third issue of the Bronx Health REACH newsletter, we want to help you help yourself and your loved ones so that you receive the best healthcare available. It is so important that we receive the care we all deserve.

The key messages in this issue of the newsletter are (1) knowing your rights as a patient; (2) becoming more actively involved in your care and treatment; (3) improving the communication between you and your doctor; (4) doing your part by following your doctor's advice, and (5) preparing for your doctor's visit. You will also find articles on recognizing and dealing with any racism you may experience in your health care; and the move towards computerized health records and how they will affect you and your health.

We've also included an article written by Dr. Neil Calman about how caring for one patient helped him recognize his own racial attitudes and biases, and highlighted the racism in the health care system.

As you become better informed and more involved with your health and treatment, we hope that the mystery of the health care system, along with the unequal care that many of us get, will begin to disappear. In this way, we are moving forward to combat racial disparity in healthcare. We, at Bronx Health REACH, are committed to doing all that we can to make this possible.

Sincerely,

Charmaine Ruddock, MS
Project Director
Bronx Health REACH

MAKING HEALTH EQUALITY REALITY

Inside this Issue

Making Health Equality a Reality

Confronting and Identifying Health Disparities

by Barbara Backer, RN, Leukemia and Lymphoma Society & Toni Carter, RN, Agape Love Christian Center

During the last several months, members of the Faith-Based Outreach Initiative (FBOI) have been learning together how to identify and confront health disparities.

The group collectively came up with a working definition of health disparities as: "a gap between the kinds and quality of care some people receive compared to what's provided to others." More specifically, health disparities means that there can be differences in the way people of color or people whose first language is not English receive healthcare, compared to whites. Many studies clearly show that people of color live sicker and die younger. On average, a male black baby born today will die seven years earlier than a male white baby born today.

Some examples of health disparities that members of the FBOI group identified included refusal to be seen by a doctor with no explanation, poor communication between doctors and patients regarding treatments like surgery and medications and excessive wait times in emergency rooms, doctor's offices, or health centers.

To empower yourself as a patient and work against health disparities, it is important to know that health-care is a universal **RIGHT**—not a privilege. It is also important to take control of your personal health. Identifying and confronting health disparities is especially difficult if you feel you cannot question the doctor, because he or she is an authority figure or your only means of getting healthcare. However, you must feel empowered to ask questions to make sure you receive the best care and outcomes possible.

There are a number of things you can do to take charge of your health. For some tips and advice, see the article below, "What Can I Do?" ■

What Can I Do?

by Neha Sachdev, Program Associate, Bronx Health REACH

If your healthcare experiences leave you with confusion and fear, you are not alone. There are ways to take control of your own health. For example, if you are honest and comfortable with your doctor and understand your own health conditions, you will be better able to command the quality of care you deserve and feel more in charge of your health. A few tips to keep in mind the next time you visit your doctor:

Make a List: Note everything you would like to speak to your doctor about, especially your symptoms. Write down how long symptoms have persisted and exactly what you feel. Keep a weekly log so your doctor can see when symptoms occur and are most intense. The clearer you are, the easier it is for your doctor to make a diagnosis and help you feel better.

Be Honest: Tell your doctor what you think is going on with your body. Be open about other medications you are taking and your lifestyle choices. Your doctor needs as much information as possible to fully understand your issue.

Bring a Family Member or Friend: This person may be able to help you take notes and will also hear the doctor's instructions in case you miss something.

Write Down Instructions: Ask your doctor to repeat or write down instructions until you know exactly what you need to do. If you do not understand something, ask for more details or another explanation.

Ask for More Information: You can also ask your doctor for additional information from a reliable source, such as a brochure, so that you can learn more on your own.

It is critical that you ask your doctor questions and are satisfied with the answers. You and your loved ones may have questions going into your visit- do not be shy about demanding answers to these. Find out how to contact your doctor to get answers to new questions or ones that may have been unanswered. Here are a few questions to consider when thinking about what to ask your doctor:

- ***What is my diagnosis? Does it make sense?***
- ***What caused my problem? Is there another possible cause?***
- ***How serious is it? How long will it last? How long until it will get better? How will it affect my health in the long run?***
- ***How does my doctor propose to treat my problem? Do I understand and accept his/her recommendation?***

continued on page 5

Bronx Health REACH becomes a Center of Excellence for the Elimination of Health Disparities

The Institute for Family Health was recently awarded 4.2 million over five years from the Centers for Disease Control and Prevention. The funding transforms Bronx Health REACH, a coalition led by the Institute, into the **New York Center of Excellence for the Elimination of Disparities (CEED)**. REACH's activities over the past seven years have included nutrition and fitness programs, a faith-based outreach initiative, a small grocer/bodega initiative, and patient advocacy and rights campaigns. Look for more details on Bronx Health REACH's future plans as a CEED in the next edition of the newsletter!

Out of the Shadows

by Neil Calman, MD, Institute for Family Health

Reprint from Health Affairs*, Volume 19, Number 1 (January 2000)*

I had been in practice in the Bronx for more than twenty years. After spending so much time in an area synonymous with urban blight, the unusual had become usual. I was no longer surprised treating patients with active tuberculosis or dealing with an astounding number of men and women suffering from hypertension, diabetes, and heart disease.

Nothing, however, prepared me for the day when James North sat quietly waiting to meet me, his new doctor. I moved from one exam room to the next with a fluidity that comes from years of practice, yet I was stopped in my tracks when Mr. North rose to his feet to greet me. His deep ebony, six-foot-three-inch frame dwarfed my pale, five-foot-three presence. The tremendous hands on his 260-pound body grabbed my own outstretched right hand and shook it firmly, accompanied by a baritone "Good morning, Doc" that reverberated through the room. He reached around and closed the exam room's thick metal door behind us. I glanced at his face, trying to see through my initial discomfort, only to be greeted by my own face staring back from the silver, reflective sunglasses he wore beneath a baseball cap that covered his head and any hair that might have been growing on it. His huge chest was tightly wrapped in a black T-shirt that, even in its largest version, couldn't stretch comfortably to encompass his pectoral girth. At that moment, I was glad for the well-practiced scripts and standard doctoring repertoire I had perfected over the years. "Good morning," I answered. "I'm Dr. Calman. What can I do for you today, Mr. North?"

He explained that he had come to see me because the cardiologist at the hospital had recommended he get follow-up care from me. He went on to tell me how he had suffered a severe heart attack that had left him unable to walk a block without resting, just one week after being discharged from the prison where he had spent more than a decade for manslaughter. He recited a list of the medications he was taking with the precision of a medical student seeking to impress his new attending physician. He also knew the names of all of the doctors who had taken care of him, including those who had consulted on him during his hospital stay. My initial admiration for his facility in reciting this information was quickly replaced by my increasing intimidation of this man, whose size was clearly not his most outstanding feature.

It was during Mr. North's second visit that I became aware of the hardship he had endured in his fifty years of life. Only after I had completed examining his right eye did he save me the embarrassment of trying to see into his artistically matched left glass eye. His chest and abdomen were scarred from what I recognized as multiple knife wounds. Now, left crippled by his recent heart attack, he was short of breath even at rest. Despite his medical problems, Mr. North took charge of his health. He managed his blood sugars precisely, which in prison had been poorly controlled by oral hypoglycemics, and his meticulous record-keeping included the exact date and time of every glucose test and insulin injection. Mr. North controlled his congestive heart failure by monitoring his weight and adjusting his diuretics accordingly. Although his cardiac function was borderline, he had been hospitalized only once, and for only three days. Mr. North became one of my favorite patients, but not because of his almost unnatural compliance with the interventions I recommended or the success I had in keeping him functioning optimally. Rather, I think I liked him so much because he continued to intimidate me, and my ability to care for him made me feel special.

(continued on next page)

I realize how hard I worked to overcome the racist feelings that made me fear him when we first met and that never allowed me to act completely naturally in his presence. I also loved watching him interact with my staff, because his commanding physical presence and intellect forced them to deliver a level of service I wished we could have provided to all of our patients.

For those of us who have made our medical lives in the inner city, fear is always just out of sight. We are rarely the victims of violence, yet it is commonplace in the lives of those we care for. Mr. North's sudden appearance in my exam room a few years ago forced me to face how vulnerable I feel at all times. But the most important lesson I learned was how essential it is to recognize my fears and racial prejudices.

I have often contemplated whether, as a physician, I can rise above the attitudes of the society in which I was born and the city in which I practice. Can I learn to see past the faces of the people I treat and deliver to every one of them the highest quality care I have been trained to provide? Can I assist my patients in negotiating the racial prejudice that lines the road between my office and the rest of the health care system? I could not provide Mr. North with all that New York's great health care institutions had to offer. He knew that. He often tried to teach me that, and was just as often amazed that I was unable to accept it. It came up time and time again when I sent him for specialty consults, diagnostic tests, or even prescription refills– the same considerations my family or I would have received were rarely given to him. The cardiology specialist who helped so much in planning a treatment regimen for his heart failure never thought of referring him to a heart transplant center. It took three separate suggestions from me before a consultation was arranged. Mr. North had Medicaid. Although reimbursement for cardiac transplants was possible, the rates were far beneath those of private payers and the likelihood of his receiving such a procedure was low. The echocardiography lab where he had a scheduled appointment sent him home after he was ten minutes late, because he had to stop and rest every block on his walk to the hospital on a particularly windy day. The pharmacy refused to refill his insulin syringes without a written prescription, even though he had been getting them at that same pharmacy for the past two years. I tried to help as much as I could. Every time I sent him to a new consultant, I called ahead to tell them how smart Mr. North was, how compliant he was and how he knew so much about his condition. I wanted my introduction to let them to see him the way I did. He needed that chance in order to get the medical care he required and deserved.

In my interactions with other health professionals I have come to believe that most of us have two types of prejudice. The first is one we are aware of, but have no ability or desire to change. We may recognize the judgments we make based on race, sexual preference, age, or another characteristic, but we do not acknowledge the invalidity of these judgments. We treat our biases as truth, perhaps admitting that they do not describe every person, but believing the generalizations are valid.

The second type of prejudice—and the place where I have been stuck most of my life—is recognizing my prejudices, realizing they are unjust, and consciously attempting to overcome them. This requires intentionally suppressing the fear and judgments that rise up inside of me and deliberately making extra efforts to treat each person as an individual. A hope I harbor is to remove all prejudice from our minds completely, so that people can show us who they are, without us having preconceived notions about them. I know I have not achieved this, because I am still sometimes surprised to meet a new doctor or lawyer working in the hospital staff and find out they are black.

Even personal victory over my own biases was not sufficient to help Mr. North get the care he deserved. The New York State Department of Health looked at the use of cardiac specialty services among blacks in the state and found that although they have the highest rate of hypertension and cardiovascular disease, the rate at which they receive diagnostic testing (echocardiography, cardiac stress testing, and cardiac catheterization) is extremely low. Lower yet is the rate at which they receive sophisticated treatments such as angioplasty, bypass surgery, or cardiac transplantation. And studies abound showing that for almost every major medical condition, the survival rate for blacks is considerably lower than it is for whites.

Society has a long way to go. Each Mr. North we let into our lives makes us more able to meet the next such patient without feeling the same prejudices. It has taken me much too long to get to this stage in my recognition and rethinking of the views I grew up with as a white, middle-class, suburban boy. The shadow of racial prejudice looms over us all. Awareness of this, coupled with constant vigilance, is needed to enable the sun to shine equally on all people. ■

Patients' Rights

by Nisha Agarwal, Staff Attorney, New York Lawyers for the Public Interest, Inc.

Every time you enter a hospital, you are supposed to receive a copy of the Patient's Bill of Rights. What are these rights and what do you do if they have been violated?

These questions provided the basis for a panel discussion at a Faith-Based Coordinators meeting at Walker Memorial Baptist Church. Meeting participants learned that the Patients' Bill of Rights is a brief list of the protections patients have under a variety of federal, state and local laws.

For example, the right to "**receive treatment without discrimination as to race**" is protected under Title VI of the Civil Rights Act of 1964, a federal law that prevents institutions that receive federal funding, including most healthcare institutions, from discriminating in the services that they provide. The right to "**receive emergency care if you need it**" is protected under the federal Emergency Medical Treatment and Labor Act (EMTALA), which requires that all patients receive a medical screening when they visit a hospital emergency room.

If patients' rights under these and other laws are violated, there are a number of steps that patients or their family members can take to address the problem.

1. Most immediately, patients should **ask for the Administrator on Duty (AOD) or a staff supervisor** and explain the situation. It is always good practice to write down the names of people you dealt with and important details about the situation so you have a good record of what happened.

2. Every hospital also has an internal complaint process. **Patients can complain in person or in writing.**

3. If patients are unhappy with the response they get through the hospital complaint procedure, they may **submit a complaint to the Department of Health**. We have listed contact information for the Department of Health (DOH) on page 6 of this newsletter.

4. Coalition members **should speak to other REACH members and REACH staff**. If information is shared within the group, it is easier to identify common problems in the healthcare system, making it easier to take collective action.

5. Finally, patients may **pursue a lawsuit or file a formal administrative complaint**.

The New York Lawyers for the Public Interest (NYLPI) association is available to answer questions in this regard. You can contact them at (212) 244-4664. The Office of Civil Rights is also willing to look into matters like these when brought to their attention.

The bottom line is that patients **do** have rights in the healthcare system. It is also important to recognize that when those rights are violated, patients have options to take action and receive the high quality health care to which they are entitled. ■

What Can I Do?

(continued from page 2)

- ***What medication, if any, has my doctor prescribed? How will it help me? What happens if I miss a dose? What are possible side effects?***
- ***Will it interact with other medication or treatments I am using? Will it interact with over-the-counter treatments or alcohol?***
- ***Has my doctor ordered any tests? What is the purpose of these tests and what will the results be used for? Have I requested a copy of my results?***
- ***What changes in my routine has my doctor suggested? How much change is needed to make a difference?***
- ***Do I know what I can do to prevent having or worsening this problem in the future? If I need help or have questions, how can I get in touch with my doctor?***

What's most important is that you leave your visit feeling satisfied with the care you received. If you do not feel that you had a productive visit, schedule a follow-up visit, or consider asking to see another doctor for a second opinion. You and your loved ones deserve to receive the best care possible. ■

Why Electronic Health Records?

by Diane Hauser, Senior Research Associate, Institute for Family Health

Your health history, current health problems, medications, height, weight and age – they're all there in your medical record. Your medical record helps your doctors keep track of essential information about you, and is especially helpful when they make decisions about your healthcare. What difference does it make if this information is kept on paper or in an electronic record?

Many healthcare experts think it makes a lot of difference. Having computerized health information available means that a complete record is secure and can never be lost or misplaced. Important information, such as a new test result, is automatically entered into the record. Electronic Health Records (EHRs) let doctors have access to their patients' healthcare information whenever and wherever they need it. If a patient has an urgent healthcare question after hours or needs to go to the emergency room, his or her up-to-date health information is available to help make the right treatment decisions.

Patients themselves are even able to see their own EHRs, to get and keep track of health information, update their records and communicate with their doctors. With the rise in rates of diseases such as diabetes, high blood pressure and asthma, EHRs will be able to help patients manage their conditions.

EHRs also have the potential to improve the care patients receive due to computer prompts that "read" the record and alert doctors to urgent information, such as a test result showing poorly controlled diabetes. The prompts, also known as 'best practice alerts', remind doctors about healthcare guidelines that should be followed– for example, cancer screenings for older patients and flue vaccines for at-risk patients. While these prompts may seem unnecessary, national studies have shown that in normal situations, recommended care guidelines are only followed half of the time.

The Institute for Family Health, a member of the Bronx Health REACH Coalition, was one of the first community health centers in the country to adopt EHRs. Using its EHR, the Institute has improved the care it provides to its patients and increased its doctors' compliance with care guidelines. Throughout New York City, State and the rest of the country, there is support to expand EHRs to better the care people receive. ■

Health Disparity Research and Resources

We have listed a few book and research articles that have more information to assist and inform you of how to successfully get the health care you need. These materials can be found online or at your local library. We have also listed the contact information for the New York State Department of Health.

- Ettinger, Alan B. & Deborah M. Weisbrot (2004). *Essential Patient Handbook: Getting the Health Care You Need—From Doctors Who Know.* New York, NY: Demos Medical Publishing.
- Korsch, Barbara M & Caroline Harding. (1998). *Intelligent Patient's Guide to the Doctor-Patient Relationship: Learning How to Talk So Your Doctor Will Listen.* New York, NY: Oxford University Press.
- Wurman, Richard Saul. (2004). *Understanding Health Care.* Newport, RI: TOP.
- Institute of Medicine. (2004). *Health Literacy – A Prescription to End Confusion.* Washington, DC: National Academies Press.
- American Hospital Association. (2007). *AHA Guide to the Health Care Field.* Chicago, IL: Health Forum.
- American Medical Association. (2001). *Guide to Talking to Your Doctor.* (Angela Perry, medical ed.). Indianapolis, IN: John Wiley & Sons, Inc.

New York Department of Health, Centralized Hospital Intake Program
433 River Street, 6th Floor
Troy, New York 12180
(800) 804-5447
hospinfo@health.state.ny.us