

Buyer Beware

by Marianne Valls

I used to wish my mother would practice what she preached. Now I think the problem's genetic because I immediately know what others should do, but I sometimes fall into the same traps I warn others against. The following experience with an unscrupulous physician makes my point.

Looking for a new primary care physician, I was delighted to discover that the same clinic that had given me excellent GYN care throughout the years had a full range of other medical services. Moreover, their doctor accepted my HMO

plan.

My first visit with him was pleasant enough. However, when he prescribed a drug called Elidel, I questioned it. He said it was winter and would help with dry skin. I protested, but he insisted, and I finally took the prescription. After all, the doctor knows best!

I later learned through TV advertisements that Elidel is used for eczema. I had heard of eczema, but never had it. Further investigation on WebMD revealed information that would have made me a more knowledgeable patient. The web site describes eczema



as skin that becomes “scratchy, itchy, red, and dry, even cracked, blistered, and leathery.”

My second visit was very unpleasant,
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for *Women*
with *Disabilities*

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Buyer Beware

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disappointing, and somewhat scary. I had run out of blood pressure medication. I called the clinic and explained my situation. The person on the phone very abruptly ordered me (and I do mean ordered) to be there at noon. I was not asked whether noon was convenient for me. In my opinion, many health care providers do not seem to realize that people with disabilities have to go to places other than doctor's offices.

Nevertheless, needing my medication, I missed a meeting that I normally attend every month. I arrived at the clinic a few minutes early to ensure I would be on time. To my surprise and aggravation, the door was locked. When I was finally let inside, it was about 1:30 before I saw the doctor. I could have gone to my morning meeting and arrived at the clinic with time to spare.

My assertiveness comes in spurts. That afternoon I decided it was time to start advocating for myself. I told my physician how annoyed I was at his staff's attitude. The first time he appeared not to hear me. I repeated myself, voicing my complaint more

forcefully. He then replied, very unsympathetically, that he had nothing to do with scheduling. In retrospect, I

Somehow, the medical profession has gotten to the top of the list of people who tend to be intimidating.

doubt the doctor understood my slurred speech or even bothered to try.

I would not be writing this article had the rude behavior of both staff and physician been the only problem. I guess the physician was annoyed by what he probably considered my confrontational behavior, for he sent a nurse into the examining room to hand me my prescriptions. His action denied me

the opportunity to question him about my medication. At the front desk, I was asked if I wanted to make another appointment. I said I would call. I never did.

Much to my surprise, when I arrived home after having had my prescriptions filled, I had four instead of the usual three. I called my pharmacist to ask what Nexium was for. He said, "for heartburn."

I can't recall ever having so much heartburn that I needed to be medicated for it. Certainly, I never complained about it to my doctor. In fact, he did not even examine me that day. Remember, doctors are human and can make mistakes. They can also be less than ethical. The onus is on us, as consumers, to become knowledgeable about our medical treatment.

Questioning your physician should be an important part of your office visit. However, it is sometimes difficult to question people you perceive to be authority figures. Somehow, the medical profession has gotten to the top of the list of people who tend to be intimidating. We must start to see health care providers for who they really are: ordinary people who aid us in making decisions about our health. *

The Onus is On Us

by Paulette M. Eberle



When Rose Ciappio needed a routine gynecological examination, she took charge of the situation. She got a friend to refer her to a doctor in her community. The doctor seemed to meet all the requirements that Rose, a wheelchair user with cerebral palsy, needed.

She called and asked what she thought were all the right questions. Was the entrance to the office accessible? Was the bathroom accessible? She

Lack of knowledge about our insurance coverage and not being specific about our needs when making appointments can be deadly.

also explained that she was a wheelchair user. The receptionist told her that the office and bathroom facilities were accessible so she made an appointment.

Usually when Rose goes to the doctor, two assistants lift her onto the examination table. In this instance, she had her personal assistant with her and did not anticipate a problem. She was wrong.

When she arrived at the office she found the entrance and the bathroom accessible, but that is where the accessibility ended.

The problems began when Rose was asked to fill out forms. She asked the recep-

tionist for assistance, explaining that she had difficulty writing because of her cerebral palsy. The receptionist replied, "That's not my job."

Her personal assistant filled out the forms. While Rose trusts her, the information required is intensely personal and many patients prefer to keep it confidential. The refusal of the clerical staff to assist with the forms made that impossible.

The receptionist escorted Rose and her assistant to the examining room where the assistant attempted to help Rose onto the examination table. The assistant realized that she could not do this alone and asked the receptionist to help. The receptionist said that she could not assist

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with lifting a patient and left them to fend for themselves.

Rose's assistant then went in search of the doctor and asked for help. The doctor said, without explanation, that she could not help.

Rose spoke to the doctor, suggesting that she meet her at the hospital to do the exam. The doctor said, "absolutely not" and left to attend other patients. Rose returned home without an examination, no prospect for one in the future and no explanation of why she couldn't be examined.

Rose was unaware that insurance companies will not pick up the much greater expense of doing routine examinations in the hospital. This lack of knowledge led her to ask the wrong question. A better question would have been, "When can you have somebody available to assist me?" (Preferably asked before the appointment)

Determined to get her exam, Rose went to The Stella C. Van Houten Women's Outpatient Center at Holy Name Hospital in Teaneck. At first, she was told her insurance would not cover her examination and she

would be better off going elsewhere to avoid out-of-pocket expenses. The staff person who told her this was unaware that Rose had secondary coverage.

When Rose related this to the advocate who had referred her, she was advised to call the Center back and explain that her insurance did cover this examination. Armed with a more thorough knowledge of her coverage, she called the Center again and made an appointment.

This time she gave more information to the clinic staff. Since she has difficulty transferring from her wheelchair, the center arranged for a 'lift team' to assist her onto the table. The examination was conducted without incident and the doctor suggested that Rose have a mammogram.

Since she hadn't made an appointment for a mammogram, the clinic could not accommodate her that day. She was also told that her insurance would not cover the test at the center. She was advised that she could get her mammogram elsewhere. Rose chose to do that.

She made an appointment for her mammogram at Pali-sades General Hospital. When she arrived, she found that the test could not be done because the equipment was not

accessible and Rose was unable to stand up for the X-ray. The technician suggested a sonogram instead of the mammogram and Rose agreed.

The simple process of obtaining a gynecological examination (for able-bodied women) took weeks for Rose Ciappio. She has learned from the experience. She has educated herself about her insurance coverage and will be able to inform a doctor's staff about this should she be told that she is not covered for a particular exam or test. She will also make appointments for her exam and a mammogram during the same visit and be very specific about her needs. As for her privacy, she has learned that this is her right and will be more assertive about these rights in the future.

Lack of knowledge about our insurance coverage and not being specific about our needs when making appointments can be deadly. Doctors and their staffs are not always trained in treating patients with disabilities and women with disabilities, too often, do not receive the appropriate care. The onus is on women with disabilities to arm themselves with knowledge to ensure that they receive the best possible medical care. *

Women with Disabilities & Allies Forum

by Patti Bennett, Mary Kay Weber & Kate Blisard

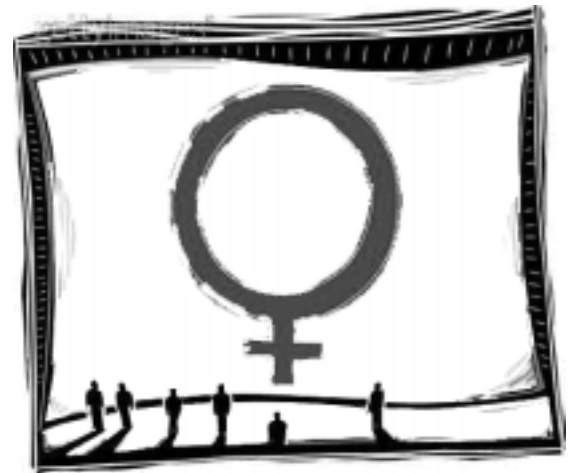
On October 17-19, 2003, we attended the Women with Disabilities & Allies Forum: Linking Arms for Equality and Justice, a conference co-sponsored by the National Organization for Women and the American Association of People with Disabilities.

As women with disabilities, advocates and members of the Women with Disabilities Health Care Task Force, we were eager to learn new things and network with new people. As Patti Bennet put it, "I really enjoyed meeting and talking to people from all over the country and telling them about our task force and what we are doing in New Jersey."

The agenda looked promising. We had many intriguing topics to choose from, such as the challenges faced by women with disabilities in mid-life, reproductive rights, violence against women with disabilities, Social Security and disabilities and the economic impact of health care for women with disabilities. Many topics on the agenda were issues the task force has been addressing.

For example, 75 percent of nursing home residents are older women with disabilities. Many of these women could live in their homes if the services they require were available in-home. Only 50 percent of older women with disabilities are receiving these services in their homes. A solution to this dilemma would be the passage of MiCASSA, which would allow the funds to follow the recipient, rather than making these services available only in an institutional setting. Health insurance with more comprehensive benefits would also help to end this situation.

For those of us who are raising a family or hoping to be parents, there is some good news. Social and health-service organizations are recognizing the right and the intent of a growing number of women with disabilities to birth, adopt, and parent children. Villanova and other medical teaching universities provide accessible and informed gynecological services. Our networking con-



nected us with the Connecticut Women and Disability Network, Inc, a group working on this issue. We learned that perspective parents could find information, mentoring, and peer support by contacting *Through the Looking Glass* at www.lookingglass.org.

Traveling back to New Jersey at the end of the weekend, we talked about the women who were working to stop violence against women with disabilities and the women struggling to get better mental health services. For Mary Kay Weber, it was about meeting and learning about other women with hidden disabilities. We all agreed there is a great deal of hope that we will live better and healthier lives in the years to come if we keep working together to find the answers and solutions. *

BY ANITA CLAVERING

Medicare RX?

On December 8, 2003, President George W. Bush officially signed the revised Medicare prescription drug legislation (S.1/H.R.1). Despite passage of the bill, it is still opposed by many members of Congress and the Senate, as well as advocacy groups such as New Jersey Citizen Action and Families USA. The White House has upped its estimate of the cost of the Medicare prescription drug program and Medicare overhaul from 400 to nearly 540 billion dollars over 10 years.

The law provides a voluntary prescription drug benefit beginning in 2006. During 2004 and 2005, people with disabilities and senior citizens may buy a drug discount card until the plan takes effect in 2006. Private insurance would pay 75 percent of drug costs up to \$2250. There will be a premium \$35 a month (\$420/year) with a deductible of \$275 per a year. When a participant's prescription bill

exceeds \$2250, they will have to pay 100 percent of their prescription costs until catastrophic coverage takes over at \$5600.

The bill offers tax incentives for employers to keep retirees on company health insurance plans. However, those opposed to this bill feel that employers will drop coverage to their retired employees once they know they have an alternative prescription drug plan.

Despite many revisions in the original bill, many Congressional and Senate leaders voiced opposition to the latest version because it would privatize Medicare. It would subsidize private insurance carriers, health maintenance organizations (HMOs) and pharmaceutical companies instead of providing comprehensive benefits. The bill authorizes HMOs to be paid \$400,000 more than they say they'll need to provide coverage. It does not allow the government to negotiate for lower drug prices with pharmaceutical companies.

Privatization of the plan would force consumers with disabilities and senior citizens into HMOs, denying them the choices that the traditional fee-for-service Medicare offers. People with dual eligibility (both Medicaid and Medicare) would be forced

into the Medicare RX Plan. Their out-of-pocket expenses will be higher on the Medicare plan than they were on Medicaid.

The AARP supported the bill with a million-dollar advertising campaign broadcast the week of the vote. Its commercials claimed that the Medicare bill "is not perfect, but it is a huge step". Many AARP members thought that its support of the bill was due to the billions of dollars that AARP makes from health insurance plans for senior citizens. In response to the AARP ads, many members tore up their cards in protest.

New Jersey Citizen Action held press conferences and conducted a phone-in drive urging Senators Jon Corzine and Frank Lautenberg to vote against the bill. Monday Morning Networks held post-card pizza parties, at which members wrote to Senators Corzine and Lautenberg as well as to Congressional representatives in their districts urging them to vote against the bill.

As a result of efforts by advocacy groups, Senators Corzine and Lautenberg voted against it. Congressmen Frank Pallone and Rob Andrews also opposed the bill, along with many of their colleagues in the House. The vote was 220 for and 215 against S.1/H.R.1. *



Statewide Conference: May 1

Partners in Wellness: Working Together to Promote Equality in Health Care for Women With Disabilities

Visit our website for a printable registration form in PDF format!
www.njddc.org/womenshealth.htm

The New Jersey Women with Disabilities Health Care Task Force is planning a Statewide Conference, “Partners in Wellness: Working Together to Promote Equality in Health Care for Women with Disabilities.” The conference will be held Saturday, May 1, 2004, at the Westin Hotel in Princeton at Forrestal Village. The conference will focus on critical health care issues that affect the lives of women with disabilities.

Conference participants will include people with disabilities, physicians, nurses and other health care professionals. There will be representatives from state offices, agencies and associations dealing with women’s health and disabilities.

Joint sponsors of this event are The Women with Disabilities Health Care Task Force, NJ Council on Devel-



opmental Disabilities; UMDNJ-Center for Continuing and Outreach Education; and UMDNJ-Robert Wood Johnson Medical School, Department of Environmental and Community Medicine. Co-sponsors are The Elizabeth M. Boggs Center on Developmental Disabilities, UMDNJ-Robert Wood Johnson Medical School, Department of Pediatrics; New Jersey Psychological Association; and Villanova University-College of Nursing, Health Promotion for Women with Disabilities Project.

Physicians and nurses who attend the conference will be receiving continuing education credits (CEUs). Please refer to the brochure for specific information regarding these credits.

There will be a \$50.00 registration fee for doctors and other professionals seeking CEUs. This registration fee will include tuition, continental breakfast, lunch, materials and a reception. The deadline for registration is April 26, 2004.

There will be no registration fee for consumers and the deadline for registration is April 26, 2004. Space is limited and it is suggested that persons who want to attend this conference register early.

Call Pat Krupka at (609) 984-4513; TTY/TDD (609) 777-3238; FAX (609) 292-7114 to request a copy of the brochure. *

SAVE THE DATE!
Saturday, May 1, 2004

Statewide Conference

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“PARTNERS IN WELLNESS: WORKING TOGETHER TO PROMOTE EQUALITY IN HEALTH CARE FOR WOMEN WITH DISABILITIES”

**The Westin Hotel, Forrestal Village
Princeton, New Jersey
Saturday, May 1, 2004**

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New Jersey Women with Disabilities Health Care Task Force:

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