

HEALTH CARE CONSUMER

NEWSLETTER of the Champaign County Health Care Consumers

FALL 1980

HSA TO INVESTIGATE HILL-BURTON!

On November 6, members of the Champaign County Health Care Consumers pressured the Champaign-Ford Subarea Board of the East Central Illinois HSA to establish a special committee to review and assess local compliance with the federal Hill-Burton assistance program. The Health Care Consumers approached the board following several complaints from local consumers.

"Recently we have received numerous complaints from residents of our area that they were not informed of their right to apply for Hill-Burton assistance as required by law," stated Carol Hollowell, spokesperson for the Health Care Consumers.

Hill-Burton is a 1946 law which awarded federal tax dollars to hospitals for capital expansion projects. Hospitals which received federal funds for capital expansion under the Hill-Burton Act are required by law to provide free and low cost care to those unable to pay. They are also required to inform these persons of their eligibility. Burnham, Carle, and Mercy hospitals all received Hill-Burton funds. Although the Department of Health and Human Services (HHS) is ultimately responsible for monitoring Hill-Burton facilities, HSAs have been specifically designated to play a role in monitoring local compliance.

"We come before this Board because under the law, HSAs are required to receive copies of annual compliance reports and reporting forms, public notices, affirmative action reports and other information from Hill-Burton facilities useful in monitoring compliance. Under the law, HSAs can also hold public hearings and develop Hill-Burton criteria for project review," explained Hollowell.

"When I went to the emergency room with my daughter, no one at the desk knew what Hill-Burton was," stated Debbie Doyle, Urbana resi-



Over 200 residents attended a CCHCC forum on birth alternatives. Story on page 6.

DOCTORS DIRECTORY BECOMES OVERNIGHT SUCCESS STORY

Residents of Champaign County have been buying copies of the 1980-81 DOCTORS/ DENTISTS DIRECTORY beyond expectations. Over 500 copies were sold in the first two weeks and several area stores sold out in only a few days. Stores which had not yet received their copies called the CCHCC office to get copies for their customers. According to co-editor Tom O'Rourke, "If sales continue at the present rate, we could be sold out before the holiday season."

Although O'Rourke and others had anticipated excellent sales, no one expected such an overwhelming response. Co-editor Diane O'Rourke cited two major factors: "First, the Directory provides residents with information that previously has been unavailable. Never before have consumers had a book that gives

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HILL-BURTON: Free Care For Those In Need

Were you ever told that you might be eligible for free hospital care? Probably not. Until recently Hill-Burton has been a little known method of assistance for low-income people struggling to pay bills for hospitalization. Even now the many Hill-Burton assisted facilities throughout the country keep a low profile regarding their Hill-Burton obligations.

Legislation passed in 1946 provided large grants to hospitals for expansion and modernization of their facilities. Rather than repay the government, these hospitals agreed to provide free and reduced cost to people of their community. This legislation is now known as Hill-Burton.

In our community there are three hospitals which have Hill-Burton obligations: Burnham, Mercy and Carle. Each year they are obliged to provide this free or low cost care to people who cannot otherwise afford to pay their hospital bills. Eligibility is determined by income, and INCOME ONLY.

At any Hill-Burton assisted facility, YOU HAVE THE RIGHT:

- to apply for Hill-Burton care at the business office, the admitting room, or the emergency room;
- to be provided with written individual notice that Hill-Burton care is available;
- to be notified within two working days of your eligibility, and provided with a written explanation if you are determined ineligible;
- to request free or reduced cost hospital care at any time before or after services are provided;
- to receive emergency services regardless of your ability to pay;

You also have the right to file a complaint if you feel you have been denied any of your rights under Hill-Burton. For information on how to apply for Hill-Burton assistance, or how to file a complaint against a Hill-Burton facility, contact staff at CCHCC. A task force composed of staff and community members is currently working to improve several areas of Hill-Burton compliance with the hospitals in this community. A pamphlet is also available from CCHCC which describes the history of Hill-Burton and the obligations held by these facilities. For more information call

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Once again Carle Clinic has avoided paying its fair share in taxes.

...and much more

MEMBERSHIP DRIVE UNDERWAY

With new staff, a new board and new energy to explore many more of the issues that effect us as consumers of health care, CCHCC is branching out in many directions. This means we need a little bit more from each of you. In order to sustain our increased activity level, we hope to triple the revenue we receive from membership contributions. And in order to create concrete change we need to make use of each of your interests and skills. These are the goals of the first annual CCHCC membership drive, launched October 8th.

The drive began with a mailing to all 1500 CCHCC members offering a free copy of the recently published DOCTORS/DENTISTS DIRECTORY to all contributing members. In the first weeks of November members will follow up the mailing with personal phone calls.

In addition, a special effort is being made to identify the issues of special interest to you and the skills you have to offer. For this purpose we have developed and enclosed the CCHCC "Issue and Talent Checklist." We plan to use the checklist to establish a membership skills bank and a system for special interest/issue mailings. We urge you to complete this form and return it as soon as possible. Remember-- CCHCC is your organization. The more involved you become in CCHCC activities, the more effective we will be.

Our membership drive ends December 5th. We are already off to a fast start but we need your support if we are to reach our goals. Please send in your membership contribution and check today.

HEALTH CARE HOTLINE NEEDS VOLUNTEERS

Consumer advocates are needed to help run the new CCHCC Health Care Hotline, scheduled to open in early December. Since its formation, the Health Care Consumers have continually received calls from local residents with requests for information and complaints about the health care system. During this time, it has become clear that consumer often are unaware of their rights as patients, misinformed about important aspects of the health care system, or lack access to crucial information. Consumers are often intimidated and confused by a system they depend on, but know little about.

Consumers in other fields can complain effectively, but health consumers have few places to turn for help. It is the goal of the Hotline to help consumers work cooperatively with medical providers towards resolving consumer complaints, eliminating communication barriers and



**CONSUMER
HEALTH
HOTLINE**

helping consumers become more effective participants in maintaining their own health. It is based on the belief that the end result will be better health care for all.

One function of the Hotline is to channel consumer complaints and questions to those who can best answer them. CCHCC is continually expanding its resource and referral files for the purpose of getting consumers the information they need. However, the Hotline's most important component is handling consumer complaints. Trained advocates work directly with consumers, furthering consumer awareness and involvement in ways to resolve complaints, and helping consumers to participate in and utilize community resources for their benefit.

The first training sessions began in November but are expected to be repeated several times a year. If you are interested in working with the Hotline please contact Myra Glassman at 384-4070.

Hill-Burton... from page 1

dent. "From what I understand," she added, "they're suppose to notify me (of eligibility) within 2 days and I haven't heard yet, and that was in August." Several other members of the audience stated that they too had not been informed of their Hill-Burton rights and had difficulty procuring Hill-Burton information.

A letter from Champaign County Board President Gary Adams encouraging the HSA to establish a Hill-Burton oversight committee was presented by county board member Susan McGrath. HSA Board Member James Culp introduced a resolution requiring the HSA subarea to "publically recruit and appoint a special committee of this board to review and assess Hill-Burton compliance in Champaign and Ford counties. The committee shall be composed of members of this board and the general public."

Following brief discussion, the motion passed without dissenting vote.

CCHCC BOARD ELECTIONS

Recent CCHCC elections resulted in election of the following 1980-81 Steering Committee members: Margie Checkoway, James Culp, Henrietta DeBoer, Debbie Doyle, Paul George, Katie Henry, Diane O'Rourke, Tom O'Rourke, Jenny Putman, Ken Stratton and Ken Zeigler.

Nominations were solicited from all CCHCC members and by nominating committee. Ballots were mailed to all members in good

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CONTRIBUTIONS ARE TAX DEDUCTIBLE

The Champaign County Health Care Consumers is funded largely through tax-deductible contributions of members and other local community residents. It is a non-profit, tax-exempt organization working on behalf of the public interest. Its work is not used for any commercial purpose. CCHCC relies upon contributions to further its programs for consumers. The HEALTH CARE CONSUMER is one of many consumer education activities supported by local contributions. Contributions are tax-deductible and may be sent to:

CHAMPAIGN COUNTY HEALTH CARE CONSUMERS
813 North Lincoln
Urbana, Illinois 61801

TOXIC SHOCK SYNDROME

High fever during or just after the menstrual period...vomiting, diarrhea, muscle pain...rapid drop in blood pressure, possibly resulting in shock...sunburn-like rash followed by skin peeling...these are the symptoms of toxic shock syndrome, the disease that has killed at least 40 women. These women, along with 350 known survivors of the disease, had one thing in common-- they used tampons.

Toxic Shock Syndrome has been identifiable since 1975, named since 1978 and linked to tampon use since last June. Recent media coverage has resulted in:

- voluntary recall of the Proctor and Gamble tampon Rely;
- advertisements by Tampax, the industry leader, suggesting tampons be changed often and replaced by sanitary napkins at night;
- an FDA statement suggesting that tampons carry a warning label advising women "to consider not using tampons or alternating tampons with napkins"; and
- many scared, confused and/or angry women.

"I read the newspapers and I can't believe this nightmare has really happened to us, to any of these women," said Margary Page survivor of TSS. "What did we do to bring this on ourselves? We didn't smoke X number of cigarettes or drink excessively or take dangerous drugs. We just used a product we had every reason to trust--like toothpaste... or soap."

Some scientists suspect the source of disease may be the synthetic fiber called caboxymethylcellulose found in most "super absorbent" tampons. This fiber is found in most brands, but Rely used it differently than the others, scattering specks of it throughout the pad. Studies indicate that Rely was used by 62-72% of TSS victims.

In research conducted before TSS was linked to tampon use, scientists have found that "super absorbent" tampons cause cells lining the vagina to pull apart, creating pockets or craters, which may be the ideal environment for bacteria growth. Some women using the larger tampons have been found to suffer tiny wounds. Scientists have so far been unable to pin down the exact cause of the damage, but carboxymethylcellulose is the prime suspect. Use of ordinary tampons was found to cause much less damage and there was no damage at all among women who do not use tampons.

For consumers interested in more information, Burnham Hospital has added a tape on

Toxic Shock Syndrome to its Tel-Med telephone information service. To hear the tape, call 337-2828 and ask for tape number 885. Tel-Med operates daily from 1-8 p.m.

Factual information and quotes taken from The Sunday News-Gazette, Oct. 12, 1980.

MEDICAL SELF CARE: A JOURNAL FOR CONSUMERS

Rev. Ed Harris, a member of CCHCC, has brought to our attention a health care magazine for consumers called Medical Self-Care. This magazine, published quarterly, is geared to health consumers interested in exercising control over their own health as well as over the institutions devoted to preserving their health. In addressing these concerns, Medical Self-Care brings together a variety of materials including lots of recent publications in health, practical advice on health and feature articles which offer thoughtful analyses on health care issues.

Most of the articles in Medical Self-Care are accompanied by a list of related books and articles as well as names and addresses of groups or individuals informed about these subjects. Also, every issue contains a section called "Access" which is a miscellaneous bibliography of current books and articles on health, and another section called "Contacts" which lists self-care classes and contact people in every state.

In addition to being a resource tool, Medical Self-Care is full of practical advice on such subjects as how to keep your own medical records, how to diagnose common health care problems, and how to organize a community health consumer group. In providing this kind of practical information, Medical Self-Care enables us, as health conscious people and health care consumers, to make changes in our daily lives and enhance our control over our well-being.

Each issue of Medical Self-Care focuses on a particular health care concern. In the past, feature articles have addressed such themes as "Power to the Patient", "Health in a Hazardous World", "Kids and Self-Care", etc. Each issue may offer seven or eight articles dealing with different aspects of a problem, in addition to five or six other articles on current subjects in health care.

Subscriptions to Medical Self-Care are \$10 per year, this includes four issues. Subscription requests should be sent to:

Medical Self-Care
P.O. Box 717
Inverness, CA 94937

HEALTH PLANNING IN TROUBLE

The following letter from the CCHCC Steering Committee appeared in the News-Gazette in October:

Hospital Administrators/ Medical Society	15
Community/Health Planning	0

No one in Champaign-Ford counties should be surprised by the medical industry's sweep of the recent HSA election. Months ago we warned that hospital administrators and the medical society were spending large sums on "community education" culminating with political endorsements of handpicked candidates and a massive effort to turn out the vote in their own behalf. No one should be surprised that the resulting board is unrepresentative of the area population and closely tied to hospitals coming up for review. No one should be surprised when the new board uses this sham of democracy as a mandate to wipe out previous reforms, or when health costs continue to rise while the problems of

quality and accessibility remain.

Citizens should be angered by these actions. This is not the way health planning or democratic elections were intended to work. HSAs were intended to bring together broadly representative citizens to address health costs, quality issues and access problems like those of the mother who called us when a local medical institution refused to treat her infant child because of a previously unpaid bill. It would be irresponsible for citizens to endorse what health planning has become.

Rather, citizens should be challenged to expand their vision and go beyond HSAs in efforts to make health planning work. The local lesson is that health planning is too important a matter of public concern to be left solely to health planning agencies such as this.

Local residents concerned about the future of community health planning are invited to participate in the Health Planning Task Force. For more information and meeting times, call Barry Checkoway at 344-5727.

Cites Failure, Frustration

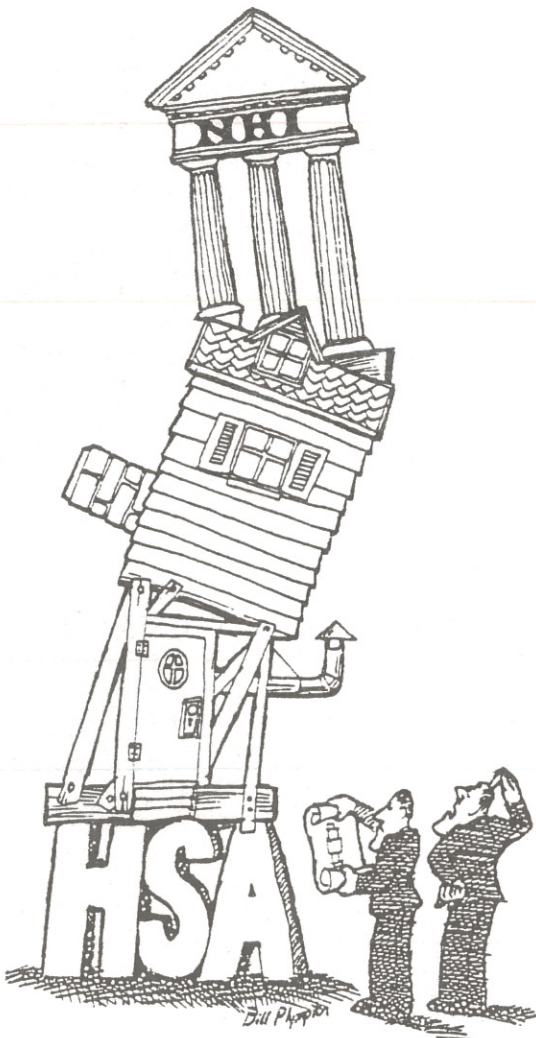
HSA President Steps Down

Breaking with tradition, John Peterson blasted the HSA as a "largely ineffectual organization" as he stepped down as President of the Champaign-Ford Subarea Advisory Committee (SAC) of the East Central Illinois HSA.

Unlike his predecessors, who often described their work with the HSA as "important" and "constructive", Peterson registered his frustrations, stating that "after eight years of observation and participation... I have come to the reluctant conclusion that Health Systems Agencies (HSA) are not likely to succeed." He cited the endless layers of bureaucratic review and accused the HSA of "failing to apply rigorous tests of review for capital projects and automatically approving plans for which no standards exist." He predicted that the HSA "process is unlikely to overcome its inability to implement anything beyond the blandest academic proposals for improvements."

Peterson urged those who will continue to be active to "prove me wrong in my predictions". But he also reiterated that he doesn't "hold out the thinnest expectation" that the future of local health planning holds much promise for consumers.

Peterson had been a member of the SAC for three years and served as President since 1978.



FEDERAL HEALTH PLANNING

BIRTHING FORUM ATTRACTS 250 RESIDENTS

Over 200 community residents attended a CCHCC forum on "The Childbirth Experience" which presented the childbirth alternatives available to parents in Champaign County. Speakers included Obstetrician/Gynecologist Larry Lane, MD; Lamaze Instructor Rose Nolan, RN; and Home Birth advocate Debbie Karplus. The film "Midwives," portraying an increasingly popular method of childbirth available in other areas, was also shown.

Speakers presented their areas of interest and then addressed questions from the audience. Dr. Lane presented a slide show of the typical birthing experience at Burnham and Mercy Hospitals. He focused his presentation on the birthing rooms he helped to establish and the choices available to patients using these facilities.

Rose Nolan gave a historical account of the Lamaze prepared childbirth experience. She also commented on the importance of having both parents involved in the birth of a child and the courses provided to parents interested in this method.

Debbie Karplus, organizer of the local chapter of Home Orientated Maternity Experience (HOME) discussed family centered childbirth in the home. She indicated that for those interested in having a baby at home, her organization provides information and support through a series of prepared meetings and literature pertinent to this topic.

All three speakers emphasized the necessity for consistent pre-natal care, good nutrition and physical exercise as the foundation for maternal and infant health care.

The film "Midwives" dramatically illustrated a birth option that is becoming widespread throughout the country, although it is not available in Champaign-Urbana. The film followed two California nurse-midwives to their home prenatal visits and to the actual home births of two infants. The film was touchingly graphic and received a very positive response from the audience. In the discussion that followed, many asked why other Illinois communities are returning to this more traditional form of childbirth and why was C-U lagging behind. Related questions concentrated on the hazards of medical interference in the birth process. General consensus was that increased consumer participation was necessary to address this issue.

The forum precipitated formation of a Women's Health Task Force. This task force

has met to discuss such issues as midwifery, DES screening, availability of contraceptive cervical caps, and formation of a Women's Self-Help Clinic. This group will continue to meet to discuss these and other issues and to plan action. The next general meeting will be held Wednesday December 3rd. For more information, contact Barrie Borich at the CCHCC office, 384-4070. Transportation and child-care will be available with advance notice.

ALL ABOUT HEALTH CARE

"All About Health Care", the first in a series of television shows on health consumer issues produced by CCHCC, began broadcasting on October 30th on cable channel 10. The first show focused on the new DOCTORS/DENTIST DIRECTORY with special guest Diane O'Rourke.

"In the past, we video-taped and broadcast our series of community forums on Cable TV in an effort to reach a larger audience," explained Mike Doyle, CCHCC Director. "However, after some consideration it became clear that most people wanted additional health consumer programming. We thus decided to move into the studios. As we learn the techniques and skills needed to put together a quality TV production, the potential of reaching out and educating the community about health issues is limitless."

In the production of the first show, CCHCC depended largely on the skills of director Bill Creswell and producer Tom O'Rourke. Together Tom and Bill visualized the show and put many long hours into making it a reality. Other participants included: Moderator- Barry Checkoway; Technical Director- Greg Baum; Graphics- Doug Fink; Audio- Mary Allen; Floor Manager- Barrie Borich; and Camerawomen- Sarah Wilkinson and Mary Ellen Page.

According to Doyle, CCHCC is already exploring other ideas for using TV to educate consumers. "We are seriously considering doing a documentary which would focus on a local health care issue. But that is further down the line. Right now, we are concentrating on making "All About Health Care" a quality program that local consumers can enjoy and still learn more about the health care system and how it works."

"All About Health Care" is believed to be the first regular television show on health consumer issues produced by a health consumer group in the nation. The first show will be aired several times in the next few months. Check local cable television listings for the exact dates and time.

UPDATE:**CLINIC AVOIDS TAXES**

Carle Clinic has once again taken refuge behind the tax exempt status of Carle Hospital to avoid paying its fair share of taxes. Already battling the IRS over taxes the clinic refused to pay on prescriptions sold to clinic patients (HEALTH CARE CONSUMER, Winter 1980), Carle Clinic refused to pay any portion of the property taxes on its new five story parking garage. The clinic, a for-profit corporation, argued that the garage is wholly owned by Carle Hospital, a tax-exempt, not-for-profit corporation and is therefore tax-exempt. Township Assessor Joanne Chester disagreed with clinic officials and assessed the clinic portion of the property taxes at \$70,000. The clinic appealed the decision to the County Board of Review, which granted Carle a full exemption. Chester appealed to the Illinois Department of Revenue which ruled in favor of Chester but failed to force Carle to pay the taxes.

Community reaction was best captured in an August 29 editorial in the News Gazette which had this to offer:

Who loses? Every property owner in Champaign County, especially those in Urbana. The Carle Foundation won because it didn't have to pay \$70,000 in property taxes it should have to pay...

What did the board of review do? It granted the foundation a full exemption — meaning no property taxes — even though a good percentage of the garage's use is related to the for-profit Carle Clinic which is not exempt from property taxes.

The board of review made its decision without an investigation even though the Illinois Property Tax Manual says: "To be exempt from taxation as a charity, property must belong to an institution organized for public charity to be used actually and exclusively for charitable purposes."

The chairman of the board of review, Wallace "Jake" Weber, even admitted that no investigation was done because "the whole thing is owned by the Carle Foundation and they're exempt under their charter."

Not true. And the board of review has ruled several times in the past that certain Carle Foundation properties are only partially exempt. For example, the board of review has determined that Carle's Material Service Building at 510 N. Busey Ave. should get a 41 percent exemption because of the division of use between the hospital and the clinic.

Chester says she'll try again next year to force Carle to pay some amount of taxes on the parking garage. But again, the final decision will rest with the board of review and the state Department of Revenue.

We hope both agencies are a little more thorough in their investigation of this issue next time around.

Elections... from page 3

standing as of September 1, 1980. Ballots were returned to the CCHCC office by November 1. The new Steering Committee members will take office at the November 19th meeting. These eleven at-large members will be joined by two appointees from each of the Consumer Health Task Forces. Together the Steering Committee will elect officers for the upcoming year.

If you were not eligible to vote in this year's election but would like to participate in the future, join CCHCC by sending in your membership dues today!

CCHCC STAFF GROWS

Barrie Borich and Loraine Cowart, both local residents, joined the staff of the Health Care Consumers in late September. Ms. Borich has been active in a number of community organizations, including A Woman's Place, the Women's Information and Resource Exchange (WIRE), the Illinois Public Action Council and Womyn Confronting Pornographic Media (WCPM). Her involvement has given her a wide range of skills such as producing newsletters, door-to-door canvassing, research and working with the media.

Ms. Cowart currently serves as President of the Bradley Park/Mt. Olive Tenants Council. Loraine moved to Champaign from Chicago six years ago. In Chicago, Loraine helped organize a neighborhood group which exposed crowded and rundown conditions in a neighborhood school. Loraine and other parents organized for over two years before forcing the city of Chicago to build a new school in the neighborhood.

Both Loraine and Barrie will be strong additions to CCHCC and its growing staff.

HEALTH CARE CONSUMER is the quarterly newsletter of the Champaign County Health Care Consumers, 813 North Lincoln, Urbana, Illinois 61801, (217) 384-4070. It is produced as a voluntary effort of community residents to help consumers stay abreast of health consumer problems and emerging solutions. Comments and contributions are invited and should be directed to the above address. HEALTH CARE CONSUMER is supported through tax-deductible donations from readers and local community residents.

CHAMPAIGN COUNTY HEALTH CARE CONSUMERS

who we are...

We are a group of active citizens who believe in the practice of participatory democracy. We are community-based and include representatives of women and minority groups, religious bodies and local elected officials, labor unions and progressive provider organizations. We believe that health care is too important a matter of public concern to be left solely to those who provide it, and that major improvements will come only with the real involvement of consumers.

what we do...

We focus on consumer participation, education, and action. Our public forums educate the general public on consumer health issues. Our leadership training workshops provide consumer leaders with knowledge and skills to carry out their responsibilities. Our newsletter helps keep consumers abreast of health care problems and emerging solutions. We work for responsible health planning and administration in accordance with federal regulations. We form Consumer Task Forces to address community health problems, currently emphasizing the problems facing low-income, minority and disabled consumers.

Directory ... from page 1

specific information about doctors and dentists in the community. The directory not only informs consumers how to choose a doctor or a dentist, but also provides information about their backgrounds, policies and fees. Second, we put a lot of work into marketing the Directory. It helps people only if it is widely used."

Since publication in early October, the Directory has been the subject of four local TV shows, several radio broadcasts and three newspaper articles. Administrators from Carle and Mercy Hospitals have cited the Directory as a fine publication and a needed community service.

In addition to the O'Rourke's, most of the work on the Directory was done by three volunteer associate editors, Nancy Beskin, Adrian Davis and Katy Murphy. Together their work resulted in "the most comprehensive of all such directories," according to Dr. Sidney Wolfe, Director of the Health Research Group in Washington, D.C.

The Directory is available in many food, drug and book stores in Champaign County or by mail from CCHCC for \$3.00. Copies can be purchased at the CCHCC office for \$2.50. New or renewed contributing members of CCHCC receive a FREE copy of the Directory along with other membership benefits.

Consumerism Under Reagan

Local consumers interested in an informal roundtable discussion about Health Consumerism under Ronald Reagan should contact Barry Checkoway at 344-5727. This session is open to all who are interested.

Join CCHCC Today!

Please send me a FREE copy of the 1980/81 DIRECTORY today. My membership fee is enclosed.

- ☐ Enclosed is \$10 - Regular Member
- ☐ Enclosed is \$5 - Low-Income Member
- ☐ Enclosed is \$_____ for _____ additional copies of the Directory (\$3 each).

NAME: _____

ADDRESS: _____

PHONE: _____

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CHAMPAIGN COUNTY
HEALTH CARE CONSUMERS
813 North Lincoln
Urbana, IL 61801

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