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August 9, 1995

Mr. Philip Johnston
Regional Director
Department of Health and Human Services
JFK Federal Building
Room 2100
Boston, MA 02203

Dear Mr. Johnston:

The recent events at Cape Cod Hospital (see attached news article and statement of from Rhonda Brooks) bring into greater focus the need to address the critical HIV care situation that exists for people living with HIV/AIDS on Cape Cod. Your efforts to address the situation could not be more timely, and we appreciate the opportunity to be part of the search for a solution.

The recent CCH episode appears to be part of a pattern of, at best, neglect and, at worst, outright hostility at Cape Cod Hospital towards people living with HIV/AIDS. Other recent experiences, while not so dramatic, bear this out, and serve to reinforce the information concerning both service and perspective of the staff and administrators we discussed at our June 14 meeting. It is clear that action must be taken to encourage Cape Cod Hospital to seriously address its lack of service to the HIV/AIDS community. The severe shortage of HIV-knowledgeable and sensitive primary care in the Mid-Cape and Upper Cape regions is critical; the lack of integrated HIV/AIDS education and awareness across the whole spectrum of CCH departments and services is acute; and the dismissive/antagonistic attitude of CCH personnel colors every experience at that facility.

We sincerely hope that part of this effort to address needs on the Cape includes serious discussion with consumers, particularly consumers who use Cape Cod Hospital. They can speak best to their experience and what is needed, and we urge you to provide HHS funding to assure a consumer presence on the upcoming New York trip, and would similarly hope that the trip to New York includes discussions with consumers there.

We also believe that the problems regarding service for people living with HIV/AIDS are symptomatic of a larger problem on Cape Cod -- the lack of availability of primary medical care in many areas. As long as this shortage exists, medical practices will be able to

avoid taking care of people with HIV/AIDS -- while hiding behind the very real problem of an insufficient capacity. Many of us in the health and human services community believe that Cape Cod Hospital should establish its own community health center that could serve as a primary care "center of excellence."

One of our biggest concerns in all the press and the public statements, and in the push for improvements to Cape Cod Hospital, is that the very real differences between regions on the Cape may not be adequately addressed, to the detriment of one particular region. We want to make sure that we not fool ourselves into thinking that addressing problems at CCH addresses problems Cape-wide.

Provincetown and the Outer Cape, as Outer Cape Health Executive Director Scott Penn pointed out recently in a letter to the Cape Cod Times, is an entirely different situation than the Mid-Cape or Upper Cape. We have already developed a multi-faceted, multi-agency partnership consisting of Outer Cape Health, Boston-based teaching hospitals, consumers, the Provincetown AIDS Support Group, PWA Coalition, mental health providers, the Provincetown Town Nurse, home health and hospice agencies, etc. We hold a regular weekly interagency meetings at both the local and regional levels to coordinate services and assure seamless referral and transportation to appropriate services for all people living with AIDS on the Outer Cape. In the absence of a facility based solution, we have forged a cooperative, referral system that works well for us, and which includes excellent primary care, world class specialty care, choice of providers, and a close-knit web of social services. Our concern is to expand and intensify this effort, not to replace it with Cape Cod Hospital.

In this context, inducing positive change in Cape Cod Hospital will not satisfy all the needs of people living with HIV/AIDS in our region. Our needs around HIV/AIDS are different from the needs of the Mid Cape and Upper Cape. Consumers here are clear that maintaining choice of service providers, in the region, on the Cape, and in Boston are essential and certainly should not be altered.

This, however, does not mean that the Outer Cape region is providing all that it could or should. Quite the contrary. Specifically, one major gap is the need to go to Boston for a wide range of basic diagnostic tests which, with minimal fiscal assistance, could be provided in the region.

Another gap is in the area of information and communication. Much of what we need to do is linked to the improvement of inter-agency communication among agencies here on the Outer Cape as well as with hospitals and other agencies in the Boston area and beyond. In addition to facilitating interagency referral and coordinated service delivery here on the Cape, this would help us coordinate treatment schedules, appointments, and discharge information with our treatment partner agencies in Boston as well as provide faster access to important medical records information from all Boston area hospitals and specialists. Further, this system could provide valuable tools such as access to the vast resources of the Internet, on-line treatment discussion groups, "video conference" access to many important treatment and research conferences, state-of-the-art case management software, and more.

Yet another issue that service providers here as well as throughout the State have been working on is increasing the support from Medicaid for AIDS-related care, particularly those which will help maintain individuals in their homes or in supported housing rather than hospitals. Many of Medicaid's programs do not adequately address the very different demands of people with AIDS. Any assistance you could provide in encouraging the State to fully address these problems, adapt their existing programs, and establish new ones, would greatly assist consumers on the Cape and across the state.

In conclusion, we appreciate everything you have done to set the stage for improvements in HIV care on the Cape. We very much would want to take this opportunity to offer our assistance and collective expertise to you and Cape Cod Hospital in this task, and to discuss our particular needs. We will be meeting among ourselves in the very near future to further develop a list of particular gaps on the Outer Cape we would like your assistance in addressing.

Sincerely,

Len Stewart
Provincetown AIDS Support Group

Victor D'Lugin
Outer Cape Consumer
Advisory Board

Scott Penn
Outer Cape Health Services

Jimmy Rann
Provincetown Positive/
People with AIDS Coalition

John Perry Ryan
ACT-UP Provincetown

Woman charges hospital guards

■ Sister of AIDS patient trades assault charges with Cape Cod Hospital security guards.

By PAULA PETERS MAHER
STAFF WRITER

HYANNIS — The sister of an AIDS patient has brought assault charges against two Cape Cod Hospital security guards whom she accuses of manhandling her, tossing her from the hospital's emergency room and placing her in handcuffs.

She and others say the incident illustrates a pattern at Cape Cod Hospital of insensitivity toward patients with AIDS.

One hospital guard has filed a countercharge of assault and battery against the woman, and hospital officials deny any wrongdoing.

But two hospital employees interviewed by the Times appeared to support the story told by Rhonda Brooks of Hyannis.

"I don't feel that any force they used was necessary. I wasn't doing anything to initiate the attack," Brooks said. "It was the most humiliating thing I had ever been through. It hurt me so badly because my main objective was to help my sister. I wasn't trying to cause any trouble."

CAPE COD TIMES
FRIDAY, JULY 14, 1985

Her sister, Brenda Soares, was taken by ambulance to the emergency room around 11 p.m. on the night of July 1, with various symptoms resulting from the late stages of AIDS, including severe pain.

Brooks was originally denied entry to the emergency room while a receptionist told her Soares was "being seen." She said she waited nearly an hour before slipping into the emergency room as a person was leaving through the doors, which are typically locked.

In nearly two hours, Brooks said, Soares never saw a doctor and the hospital staff had barely attended to her.

She said she found her sister scared and alone in a dark cubicle, curled up in a fetal position on a hospital gurney, shivering and complaining of pain. Brooks said Soares told her she had called out for a doctor or a nurse several times to get a blanket, but no one responded.

"She told me every part of her body hurt her," said Brooks, who believes the staff was avoiding her sister because she has AIDS.

Hospital spokesman Van Northcross denied the claim. Considering that more than 240 people were treated during that shift, he said, the patient was treated quickly and correctly.

But he could not comment further on Soares' condition or treatment because of patient confidentiality. He also said the hospital has launched an investigation into the incident.

Brooks had hoped that her sister would be admitted to the hospital.

PATIENT

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But a nurse told her to take her sister home and that there was nothing the hospital could do other than give her a prescription for pain.

Brooks called a cab, but when the cab arrived 20 minutes later, there was no prescription, and no paperwork had been generated to release her sister.

When she asked a nurse about the prescription, Brooks said the nurse was very rude and ordered her out of the emergency room. She refused to leave.

Northcross said security was called to the emergency room because Brooks was being disruptive and was using foul and abusive language. Northcross said the parents of a child being treated took their child and left because of the disruption.

The nurse called a security guard, whom Brooks claims grabbed her, twisted her arms behind her back, and tossed her through the emergency room doors to the floor of the lobby. Brooks said she turned on the two guards, who were still coming at her, and swung at one of them to defend herself.

"I hit him, I don't deny that, but it was in self-defense," she said. "Then both of them threw me to the floor and punched me in the back and handcuffed me."

Soares said that her sister was never antagonistic and that she was begging the nurse to allow Brooks to remain with her. She said the nurse was rude.

Northcross said patients in the emergency room are allowed to have a friend or family member stay with them at the discretion of the staff. He said a person may be asked to leave if they are being disruptive.

Two hospital workers who witnessed the incident spoke to the Times on the condition that their names not be published.

A staff person stationed inside the emergency room when the incident took place said it was a very busy night. She said that she overheard a nurse being rude to Brooks but that she never heard Brooks use foul language. She said the nurse ordered Brooks to leave, and when Brooks objected the nurse called security.

"There was really no reason for her to leave; she wasn't doing anything to cause a disturbance," the staff person said.

The worker said she did not believe the nurse was insensitive to Soares because of her condition but had become short-tempered because of the busy shift.

Another hospital worker said she saw a security guard burst into the lobby "like a raging bull," twisting Brooks's arm behind her back.

"He pressed her face against the floor and twisted her arms behind her back to cuff her," the worker said.

She said Brooks did not appear to be aggressive or hostile and asked the guards to "please" retrieve her cigarettes and other contents of her purse that had spilled out onto the floor.

Barnstable Police Detective David Myett said police were called to the hospital at 1:30 a.m. Myett said he report indicates that a security guard was assaulted and that he

handcuffed a woman before the officer arrived.

He said the officer could not make an arrest because he did not witness the attack and ordered the woman released.

Brooks's complaints against guard Edward "Muffy" Clough and John Dorr, and Clough's cross-complaint against Brooks, are pending in Barnstable District Court. Those complaints do not become public until after a hearing before a clerk-magistrate.

John Perry Ryan, a spokesman for the Provincetown chapter of the AIDS Coalition to Unleash Power, ACT UP, said the incident

represents a pattern at Cape Cod Hospital that includes various complaints, such as "failure to treat, refusal to admit and flimsy care."

He said he is aware of efforts by the hospital to improve the situation, but he does not feel they have been effective. He said busloads of AIDS patients still bypass Hyannis to be treated at Boston hospitals.

Northcross said the hospital has made great strides dealing with AIDS patients. Since November 1992 the hospital has offered regular sensitivity and clinical training to doctors and the medical staff who deal with AIDS patients.

Statement by Rhonda Brooks concerning the events at Cape Cod Hospital, Hyannis, that took place beginning around midnight on Saturday, July 1, 1995

I, Rhonda Brooks, went to Cape Cod Hospital in a friend's car after my sister, Brenda Soares, an AIDS victim, became seriously ill and had to be taken to the Emergency Section by ambulance. I went to the reception desk and explained who I was and why I was there. The receptionist said she would check on my sister's condition for me. She told me that Brenda was being seen by the doctor and that I couldn't go back to see her, but that I would be kept informed.

Time went by, about 45 minutes. I asked the receptionist to check again. She replied that she was busy but would call when she could. I could see where the entrance to the treatment area was because people were coming out there, so at a certain point I went in that way, looking for my sister.

I found her in a room lying on a gurney in a fetal position. She was shivering. She was very hot to the touch, as if she had a fever. I took some sheets and placed them over her. She kept saying that she had called out for a doctor or nurse telling them she was cold, but no one came to bring her covers. She said every part of her body hurt. I sat with her and comforted her, and asked if the doctor had seen her. (I learned later that Brenda had been X-rayed before my arrival, and that "something" had been observed on a lung.) Brenda said no one had come to examine her. Medical personnel were passing by outside the room, smiling and talking, sometimes looking in but going on by. Some time went by. A nurse practitioner came in finally and stated she was going to let Brenda go home. Brenda said, "You're not going to admit me?" The practitioner said, "No, we have no reason to keep you." Brenda said, "I can't breathe." Her breathing was heavy. The practitioner said, "We'll give you a prescription for cough syrup." Brenda said, "I'm in paid." The practitioner said, "We'll give you something for pain, too."

I asked the practitioner if it would be all right for me to phone for a taxi to take Brenda home. She said yes, and told me she would write out the prescriptions, and by the time the taxi came, everything would be ready.

I phoned for a cab and was told it would arrive in twenty minutes. I went back to Brenda's room to wait. Time passed. Brenda asked about the prescription, so I went to the doorway looking for the practitioner, who happened to walk by. I said, "Excuse me, doctor, is the prescription ready?" She said, "Yes, I'm writing it up now." I went back in the room and sat down. Again more time passed. Someone asked if anyone had called a taxi. I went back to the doorway again. A nurse was going in a room. She stopped, and said to me, "Excuse me, may I help you?" in a very nasty voice. I said, "Yes, my cab's here, and I want to get my sister's prescription." She said, in a very nasty tone, "That's your problem." I said, "Excuse me, Miss, I didn't disrespect you." She said, "Matter of fact, get in the lobby." I said, "Miss, I'm not going anywhere. I just want to take my sister home. Our cab's here." She said, "Didn't I tell you to get in the lobby?" I said, "Miss, I'm not going in the lobby. I want to take care of my sister, and get her prescription, and go to the cab waiting there so we can go home." She said, "I said move it!" in a very nasty tone.

I walked back into Brenda's room, telling the nurse I wasn't going. She said, "I'm calling Security." I said, "Call them, because I haven't done anything." She called them. Meanwhile, Brenda was yelling, "I have fullblown AIDS, my sister's here helping me."

By this time, one security guard had shown up (his name was Edward Clough, called Muffy). He came walking by the door, not knowing which room to go to. He asked the nurse what the problem was and which room it was, so the nurse showed him the room and told him, "I want her out of here--now." He came into the room. Brenda told him, "My sister hasn't done anything, it's that nurse out there, my sister hasn't done anything, but help me, I have full-blown AIDS. We just want the prescription and to go home." I told Brenda to calm down. She was hyperventilating. I said, "Officer, can I explain something to you? I'm not doing anything. My sister has AIDS, and I just want the prescription and to take--" Before I could finish my statement, he yelled, "Shut your mouth. If she [the nurse] wants you out of here, you're out." Then he came toward me. Brenda was getting up off the gurney. As I went toward her, he was coming toward me. I was trying to calm her. Then I was moving toward the door, to get away from Brenda because the security guard was in a rage, and I didn't know what he was going to do. As I was going by him, toward the door, he pushed me. As I got to the doorway, he hit me on the shoulder. He followed me into the hallway. I was still attempting to

explain things to him but he was not listening. He threw me up against the wall, grabbed my arm, twisting it behind my back. I turned around so as to release my arm from his hold. By this time Brenda had come into the hallway, holding her arms on her stomach, barely able to walk. The other security guard had shown up, and both of them grabbed my arms, put them behind my back; I was lifted up on my toes by my arms. I turned my head; because one guard was short, I could see Brenda past him. She was screaming, "Please let my sister go, we just want to go home, please. We haven't done anything." I told Brenda, "Go back and lie down. Get on the bed, please. I'm all right."

The guards took me to the doors leading out of the emergency room to the lobby. One guard opened the door, while still twisting my arm, then both guards threw me through. I went forward, and turned; the guard, Edward Clough, was still behind me. I was frightened and angry, and hit him in the face. Both guards charged at me and threw me to the floor. They twisted my arms behind my back. They handcuffed me. I was being hit on the back either by fists or knees or both. I could not see; my face was pressed to the floor. I heard a voice say, "You better not hit her, I'll knock you out." I found out that this person was a man by the name of Joe Joe. The guards grabbed me by the handcuffs and lifted me. I noticed my pocketbook and belongings had fallen to the floor. I asked them to please get my things that had fallen out. The tall security guard, John Dorr, told me, "Fuck you, bitch, you're not getting a fucking thing. Fuck your pocketbook." They took me outside to the ambulance entrance. They slammed me down on the step, and said they were calling the police because I was going to be arrested.

A police officer came. He asked me what had happened. The guard said I had hit him, and I told the officer I had hit him only after he had hit me. The officer said to me, "What does this say on his shirt?" I said, "that he's a security guard." The officer said, "It says 'state'," meaning he was an officer of the state. (Clough is the one he was referring to.) The officer told me that whatever the security guard told me, even if it was to leave, then I had to leave. I told the officer, "Excuse me, I don't care if he's an officer of the planet, that doesn't give him the right to hit me." The officer said he was going inside the hospital to see what had gone on. He placed me in the back seat of his car. The driver side door of the cruiser was open. When he came back from the inside of the hospital, he told the security guard that he couldn't arrest me, and told him (Clough) he had to remove the handcuffs. He said he had no reason to arrest me. He said, "She has to be released on her own recognisance." (This officer was named Alexander.) Clough opened the car door, and I got out. The officer told me I could not go back in the hospital or he would arrest me. He then told Clough to remove the cuffs.

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Rhonda Brooks

I told the officer I had no intention of going back in, I just wanted to know how my sister was. The officer took my name and number, and told me my sister was leaving at the front entrance. I ran around to the front, but Brenda had already gone in the taxi. I knocked on the window of the Emergency Section, and some people came out. I asked them to call me a cab. A young man said he would take me home. He gave me a ride to my mother's house. On the way he said he was the one who had spoken up at the hospital. He said he saw the security guards ready to punch me, and then he had spoken up. He said he would testify if necessary about the incident. A lady companion of his also witnessed what happened.

Cape Hospital Said to Lack Sensitivity

By Doug Fraser

Last summer, Dick Patulak was asked by a nurse to administer medication to his partner, who had AIDS. His partner had come to the emergency room at Cape Cod Hospital with internal bleeding and a blood infection, and was immediately transferred into an isolation room.

"She stood in the doorway, and asked me to bring it in to him," recalled Mr. Patulak, who said it was obvious the nurse did not want to touch his partner.

Mr. Patulak's testimony highlighted a press conference this week in Provincetown by HIV consumer advocacy groups and Cape Codders Against Racism protesting what they say are discriminatory patterns of behavior at the hospital.

Mr. Patulak said his partner was so upset by the insensitivity of the staff in the emergency room that he refused to return there, even for an emergency. Instead, the next time, he bypassed the hospital, switching at the Burger King off Route 6 in Barnstable from a Provincetown rescue vehicle to one bound for a Boston hospital.



At a press conference in Provincetown Tuesday, Richard Patulak testifies that his partner was ill-treated while in the emergency room at Cape Cod Hospital.

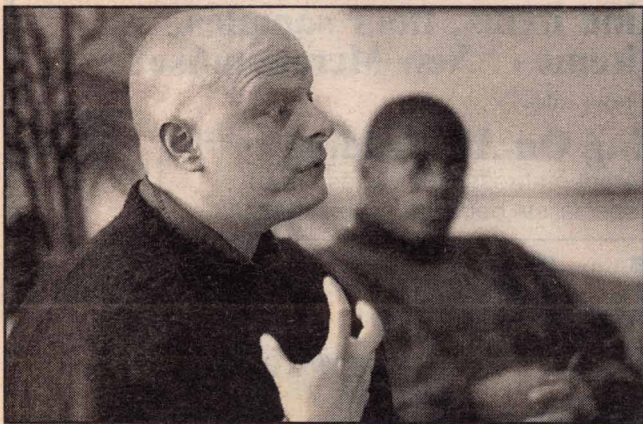
Staff Photos by Barry Donahue

"While we were crossing the bridge," said an emotional Mr. Patulak, "he told me he'd rather die on the bridge, than go back there."

"What is happening at Cape Cod Hospital is a willing disregard for people of color and those living with AIDS," said Victor D'Lugin, the chairman of Provincetown Positive/People with AIDS and a recent winner of the prestigious Harvey Milk Award for gay/lesbian activism. "It is clear and unequivocal that they don't want us there."

The press conference included representatives from Cape Codders Against Racism, Provincetown Positive/People with AIDS Coalition, the Outer Cape Consumer Advisory Board and Cape Codders Against Racism. They were concerned that Cape Cod Hospital may be excluding those patients it found least desirable, including the poor, people with AIDS and HIV and people of color. They want the state Department of Public Health to make sure the hospital has policies in place before it approves the proposed merger with Falmouth Hospital and the consolidation of health services under the Cape Cod Health Care umbrella.

Cape Cod Hospital spokesman Van Northcross said



Scott Penn, executive director of Outer Cape Health Services, said he is concerned that the consolidation of health care under Cape Cod Health Care could create a monopoly which would systematically exclude the poor, those suffering from AIDS and HIV, and people of color.

Hospital

(Continued From Page 3)

many of the incidents cited at the press conference happened years ago, and that hospital officials had taken steps to remedy each incident as it was reported to them. Some of the case histories were not familiar to him, but he said all such incidents should be reported to the hospital and that there are specific policies in place to deal with them as they occur.

Mr. Northcross said the hospital is always open to input from any group or individual. He said any concern people have would be addressed.

He felt the hospital was being held accountable for what had happened in the past, and was annoyed no mention was made nor credit given for changes that had been made recently.

He cited the hiring this year of an HIV coordinator to work with patients, creation of a consulting service staffed by two AIDS-expert physicians from Massachusetts General Hospital, the ongoing Family Care Project which provides home-based care for AIDS patients, formation of an AIDS Action Committee, and educational sessions for nurses, physicians and

other professionals associated with the hospital.

But, he said, a shrinking pool of available federal dollars means money only goes so far and has to be divided among many competing interests.

"We have 20 different clinical departments and we hear the same thing from breast cancer patients, prostate cancer patients," Mr. Northcross said. "We're a community hospital. We have to treat everyone regardless of their ailment or ability to pay. We can't pick and choose who we'll treat, like the teaching hospitals in Boston."

He said there were few if any community hospitals which were as good as the teaching hospitals in Boston and that most AIDS patients statewide bypass their community hospitals for the university hospitals.

At the press conference, Elizabeth Burkes of Cape Codders Against Racism said that the hospital's medical staff is 99 percent white. Mr. Northcross confirmed that figure. He said the hospital had an aggressive hiring program to recruit minority doctors and health professionals, but there

was a problem attracting them to an area that is overwhelmingly white. The hospital does not recruit solely by color, he said:

"You can't just take anybody to do brain surgery."

The problem, said the coalition, goes beyond numbers and incidents. Members say it is one of perception, and that the hospital needs to reassure those in the community that it will be responsive to their concerns. Otherwise, the institution will have effectively shut them out.

"As an African-American and a man who is HIV-positive, one of my greatest fears is having to go to Cape Cod Hospital for treatment," said Douglas Brooks, of the Provincetown AIDS Support Group.

Mr. Northcross said that public perception is based on real incidents that happened in the past. He argued that the hospital has changed, and that people have to give it a chance. He said the hospital has treated many patients with AIDS who have responded positively to the staff's care and concern, but admitted that public perception is hard to change.

"If you contracted food poisoning in a restaurant, would you ever go back there?" he said.