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# *Public Hearing*

before

## NEW JERSEY LEGISLATIVE COMMISSION FOR THE STUDY OF PAIN MANAGEMENT POLICY

*“Issues related to patient access to acute and chronic pain management and treatment,  
including pain in patients with terminal conditions”*

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**LOCATION:** JFK Conference Center  
Edison, New Jersey

**DATE:** September 16, 1998  
7:00 p.m.

**MEMBERS OF COMMISSION PRESENT:**

Assemblywoman Charlotte Vandervalk, Chairperson  
Assemblywoman Joan M. Quigley  
Joseph Aisner, M.D.  
Douglas Ashendorf, M.D.  
Harold Bobrow, R.Ph.  
Caryl A. Distel, M.A.  
Jack Goldberg, M.D.  
Paula Sue Krauser, M.D., M.A.



**ALSO PRESENT:**

David Price  
Commission Secretary  
*Office of Legislative Services*

*Hearing Recorded and Transcribed by*  
The Office of Legislative Services, Public Information Office,  
Hearing Unit, State House Annex, PO 068, Trenton, New Jersey

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**ASSEMBLYWOMAN CHARLOTTE VANDERVALK (Chairwoman):**

Good evening. We are going to get started, and I thank you for your patience. We're running a little bit overdue, but we don't have all our Committee members here, and we are expecting a few more later. I thank those of you that are here to testify.

I would just like to remind the members that the gray microphones are for amplification and the black microphones are for the recording unit to make sure that the words are being transcribed.

Lowell Arye? Arye (indicates pronunciation). I think that is the hot seat. (directing witness to witness stand)

Arye, did you say?

**LOWELL ARYE:** Arye. (indicates pronunciation)

ASSEMBLYWOMAN VANDERVALK: Arye

MR. ARYE: Yes.

ASSEMBLYWOMAN VANDERVALK: Thank you. Good evening.

MR. ARYE: Good evening. My name is Lowell Arye, and I am the Executive Director of the Alliance for the Betterment of Citizens with Disabilities -- ABCD. I want to thank the Chairperson and other members of the Commission for allowing me the opportunity to testify on ways to improve patient access to effective acute and chronic pain management and treatment.

For a little history, ABCD is a statewide agency representing member agencies that provide an array of community services to more than 4000 people with multiple physical and developmental disabilities, and they

provide educational information to more than 20,000 individuals. On the coversheet, you will see a list of the member agencies.

ABCD members are dedicated to improving the lives of people with multiple physical disabilities. They provide an array of community services to a variety of individuals with multiple physical disabilities -- individuals with normal cognitive functioning, as well as with low cognitive functioning. The individuals we are talking about are people with spina bifida, cerebral palsy, autism, mental retardation, and many of them are dually-diagnosed with different pieces of those disabilities.

For these individuals, the issue of pain and access to acute and chronic pain management is extremely important. Unfortunately, access to many services, including pain management, is difficult for this population. Any recommendations that this Legislative Commission presents next year should include the need to increase access for knowledgeable health care, and other providers in the field, for people with multiple disabilities and their access to pain and pain management issues.

Most of the research and information related to pain and pain management for this population is based upon work for -- in people with cerebral palsy. There is a dearth of information about these issues for people with multiple physical disabilities, and what I am going to do is focus in on the issues related to cerebral palsy.

For people with multiple physical disabilities, there's really no information about the risks of developing pain or about preventing it, especially over a long period of time. In a recent study prepared in Ontario, Canada by the Ontario Federation for Cerebral Palsy, researchers asked that

informants discuss issues relating to the timing and nature of physical changes. The informants mentioned lifestyles very frequently. They cited a lack of regular exercise and poor nutrition for things such as circulatory and respiratory problems. They also listed physiological issues as relating to pain, including imbalance in muscle development, abnormal stresses on bones for longer periods of time leading to wear and tear on joints, and changes in gaits.

For people with cerebral palsy, musculoskeletal complaints are widespread. Commonly, they are attributed to arthritis, but there is not even any clinical evidence to show that arthritis is the cause of the pain, and that they even have arthritis. There is little or no research evidence to show that musculoskeletal or arthritic pain complaints occur earlier in life for people with cerebral palsy than for their nondisabled peers. We also don't know if people with cerebral palsy are at greater risk for developing age-related arthritis.

Researchers have not studied the long term impact of treatment during an individual's younger years. Some clinicians suggest that weight-bearing on poorly developed joints, aggressive therapeutic mobility activities, repetitive movements, poor preparation or maintenance of these activities may lead to joint pain, muscle pain, or weakness.

There is little information about strategies to maintain endurance over a lifetime for an adult with multiple disabilities. And as we are seeing with the general population, people with cerebral palsy and other multiple disabilities are aging, and we're now seeing people 40 to 60 years old who have cerebral palsy and other physical disabilities. So, we are going to see this as a major issue for this population.

When asked to list treatment and intervention strategies commonly used in prevention of secondary conditions, informants mentioned -- in this Ontario study -- maintenance programs for range of motion, mobility, and flexibility. Therapeutic techniques such as trigger point therapy, massage, and other related manual therapies could be helpful as well. Occupational therapists can also recommend ergonomic and accessibility modifications to ensure continued optimal mobility.

Excuse me. (witness drinks water)

ABCD has been very concerned about the issue of Medicaid Managed Care for this population and New Jersey Care 2000, which the State is going to be implementing, probably, in 1999. We are concerned that it doesn't go far enough for these therapies. We really would like to see a little bit more flexibility in the issues of therapies -- occupational, physical, speech therapies -- for this population, in New Jersey Care 2000. We would hope, prior to the implementation of the New Jersey Care 2000, that this Commission takes a look at this issue for therapies for people with disabilities and the issues of acute and chronic pain management.

Also, I would like to recommend to this Commission that you look at a report that was prepared back in 1986 by the U.S. Department of Health and Human Services. It was mandated by what was called the Disability Benefits Reform Act of 1984, Public Law 98-460. This particular study that was done in conjunction with the National Academy of Sciences basically looks at a variety of issues as it relates to Social Security and disability, and their use in the issue of pain and subjectivity of their pain determinations. At the same

time, it also provided state-of-the-art information back then as to issues of preventing, reducing, and coping with pain.

It is 12 years old, so therefore it is no longer “state of the art”, but given that the populations we’re talking about, people with multiple physical and very severe disabilities who do not work and will never go to work, we’re talking about that population. That was really the preemptive study on that mandated by Congress.

I know I am raising more questions than answers here. We recommend additional research, both at the State level as well as nationally, on issues about understanding the impact of therapies on pain and pain management. For example, how can assistive technology, selective exercise, or the use of special equipment be effective in the prevention of pain or fatigue in persons with multiple disabilities? What about full- and part-time users of wheel chairs? What is the impact on back pain, knees, hips, etc?

One of the pieces that is raised in the legislation that mandated this Commission is the issue of medical schools. It’s not just the medical schools who need to be provided with the curriculum changes. It’s all allied health and other health care professionals. There is, as I said before, a dearth of information about this, and there is a dearth of information with regards to people with disabilities in the health care field. And there is a need for that. I would recommend that you all take a look at that, not just with medical fields but other allied health professionals.

Thank you, and I would be happy to answer any questions.

ASSEMBLYWOMAN VANDERVALK: Thank you for being here. I have not had the opportunity of meeting you. You're very new in your position.

MR. ARYE: Just a year.

ASSEMBLYWOMAN VANDERVALK: I didn't realize you were there that long.

MR. ARYE: Yes.

ASSEMBLYWOMAN VANDERVALK: Okay. Time flies.

MR. ARYE: That's okay.

ASSEMBLYWOMAN VANDERVALK: I had put some legislation in, which is traveling through the system now, to have a fellowship -- fellowships, plural -- established for people with disabilities, so that we have people specifically trained to service that population. I have not had a chance to talk to you about that, but that has started to move.

MR. ARYE: And we're very well aware of it. We truly support it, Ms. Vandervalk.

ASSEMBLYWOMAN VANDERVALK: Now, does that go far enough?

MR. ARYE: It doesn't, unfortunately. All that does is create fellowships for people after their medical school, and so the problem is that's for speciality care after medical school. What we're talking about -- what I am thinking of is to go even further and to really have modules within medical schools and allied health professional schools to provide information about developmental disabilities. For example, there are many university affiliated training programs that provide services -- Deborah Spitalnik is the Executive

Director of the Bach Center and the UAP here in this state. There is actually a book called "Children With Disabilities" that was written by Mark Batshaw, when he was at Children's Seashore House, that deals with those issues. It's over a 1000- page book that deals with specific issues about spina bifida and cerebral palsy, mental retardation, etc. It's specifically for people who deal with these children. Unfortunately, there's not another book for the elderly or the adults with disabilities. That's used for -- not just the fellowships -- for the just -- training in general. I would definitely recommend that you go a bit further on that. From my standpoint, I think the fellowships are a very good start, and we really do support that. I also know that there's also the commission on medical care for developmental disabilities legislation, which is in conjunction with that. We are very interested in that and would love to speak to you about it in the future.

ASSEMBLYWOMAN VANDERVALK: Okay, thank you very much.

Yes, Dr. Krauser.

DR. KRAUSER: Do you have any recommendations about the use of pain medication in chronic care?

MR. ARYE: Unfortunately, I don't. I have always believed that I shouldn't speak about an issue that I don't really know about, so I will say that I really don't know a lot about it. I am certainly sure that folks at Matheny School and Hospital, who are one of my member agencies, would be happy to speak with you all about it. I think that the problem, unfortunately, is that there is relatively little information out there. There is little clinical

evidence, as well as research in general, about that. People have utilized it, but it is sometimes difficult to know.

ASSEMBLYWOMAN VANDERVALK: Thank you very much. I am sure we will talk further about points you brought up.

Barbara Benson.

**BARBARA G. BENSON:** I wonder if I should take my water now.

ASSEMBLYWOMAN VANDERVALK: Sure.

MS. BENSON: Thank you for being the Pain Commission, because this is a wonderful opportunity for all of us to be a part of this very important study. My name is Barbara Benson, and I am a Vice President of the New Jersey Chapter of the American Massage Therapy Association, and I am also their Governmental Relations Chair.

AMTA is the largest international, member-driven organization representing the massage therapy profession. Founded in 1943, it has over 30,000 members in over 100 countries. The AMTA has chapters in all 50 states, the District of Columbia, and the U.S. Virgin Islands. AMTA New Jersey is headquartered in Middlesex, New Jersey and represents over 1300 members. Its professional members have demonstrated a certain level of skill and knowledge through education and testing.

Therapeutic massage is increasingly being recognized and recommended by physicians as an effective complement to traditional medical treatment in the areas of illness, injury, and pain.

As the use of massage and other alternatives or complementary -- and again, it's interchanged, you know, depending on what group you are speaking to -- in addition to these alternative practices to traditional health

care have increased. AMTA continues to develop and advance the art, science, and practice of massage therapy by helping to create a climate which is both protective of the consumer and supports the practice of massage. Currently, proposed regulation (*sic*) S-1047 and A-843, which would regulate massage, bodywork, and somatic practice, is an example of that direction. It is hoped that, as we continue to shift into a wellness centered health care system, alternative or complementary practices will be integrated into western medicine.

There is a large body of research which supports the efficacy of massage therapy. The National Institute of Health, which founded the Office of Alternative Medicine in 1992, established 10 centers in the United States to study alternative therapies, including massage, for a variety of ailments from women's health and chronic illness to pain and addictions. All are affiliated with major institutions, from Harvard Medical School in Boston, Massachusetts to Stanford University in California. Studies that were funded with NIH grants include cancer patients, HIV exposed infants, and postabdominal surgery patients. In addition to the NIH research, the Touch Research Institute of the University of Miami School of Medicine has 55 studies that have been published or are underway relative to the effects of massage therapy in clinical situations, which include posttraumatic stress, severe burns, migraine headache, mental depression, carpal tunnel syndrome, Down's syndrome, premenstrual syndrome, and lower back pain. Working in conjunction with Duke University, researchers have measured the body's biochemical levels after massage therapy and found a dramatic decrease in the levels of cortisol, nor-epinephrine, epinephrine, and dopamine.

AMTA supports research through the AMTA Foundation, which helps fund and collaborate with the Center for Alternative Medicine Research at Boston's Beth Israel Deaconess Medical Center, which is conducting a study on the use of alternative treatments, including massage for lower back pain.

Massage doesn't just feel good. Massage has many health benefits, and it can be an important factor in attaining and maintaining wellness. It reduces the heart rate and blood pressure, increases blood circulation and lymph flow, relaxes muscles, and improves range of motion. Massage can increase serotonin and endorphins. Serotonin influences blood flow, and increased endorphins affect pain perception, enhancing medical treatment. Therapeutic massage can also improve job productivity and morale and has helped reduce employee absenteeism, motivating many companies to provide massage therapy at the workplace.

It would be difficult to find anything else that has such a wide range of benefits that will encourage and enhance the natural healing process of the body. Massage therapy is both noninvasive and nonpharmacological. Therapeutic massage can help the body deal with daily stresses and to foster good health.

The legitimate proof substantiating the benefits of massage therapy abounds, and I encourage the Commission to support the integration of massage therapy in the approach to chronic pain management and treatment. The potential economic benefits can be easily seen with a collaborative utilization of medicine, pharmacology, and complementary or alternative therapies.

As the American Massage Therapy Association continues to develop and advance the practice of massage therapy in a caring, professional, and ethical manner, it is our hope that we will be partners in promoting the health and welfare of humanity.

And I thank you very much.

ASSEMBLYWOMAN VANDERVALK: Thank you.

Assemblywoman Quigley.

ASSEMBLYWOMAN QUIGLEY: Thank you, Madame Chairwoman.

I have some questions if you don't mind, Ms. Benson.

MS. BENSON: Sure.

ASSEMBLYWOMAN QUIGLEY: If you don't mind?

MS. BENSON: Absolutely.

ASSEMBLYWOMAN QUIGLEY: How are your members compensated for services that they now provide to ill people, whether they are institutionalized or at home? Does insurance cover it? Do the government programs cover it?

MS. BENSON: Absolutely not.

ASSEMBLYWOMAN QUIGLEY: Should they?

MS. BENSON: Well, one would like that, but I think it's more important, from our point of view, that we make it accessible to the potential consumer than to concern ourselves with the insurance part of it. We certainly want it to be that way, but if that is not to be at this time, it is much more important that we have qualified, certified, and appropriate people doing the work and the ability to practice.

ASSEMBLYWOMAN QUIGLEY: If we were to reach a position where there are certified therapists -- people who are involved in continuing care of people with chronic illnesses or even short term problems -- I think it would be difficult to have only people who could afford to pay for services, privately, receive them. Whereas others who might not be able to afford to pay you directly would not be getting them. Does your association have any opinion on that?

MS. BENSON: As an association, they don't take an opinion on it, per se. What they encourage is massage therapy as an alternative or -- I really should say complementary modality to be used along with, or as an adjunct to, other modalities.

ASSEMBLYWOMAN QUIGLEY: But who would pay you?

MS. BENSON: Well, right now the people themselves pay. I would love to have a world where we don't have to pay for any of these things, but that is not a reality. Certainly, if given the right set of circumstances and the opportunity, it would be wonderful that -- that would be, in fact, -- if you were to envision an integrated clinical situation where you can have all of these things and have the insurance for it-- Certainly, I would love that.

ASSEMBLYWOMAN QUIGLEY: Well if you have--

MS. BENSON: That would be a wonderful thing.

ASSEMBLYWOMAN QUIGLEY: If you have statistics or any impressive information that would show that massage eases pain and contributes to healing, certainly that would be something we would like to consider.

MS. BENSON: Well, we can provide that all to you. I don't know if you are familiar with Tiffany Field who runs the Touch Research Institute--

ASSEMBLYWOMAN QUIGLEY: No, I am not.

MS. BENSON: Okay. I would love to have her -- in fact, she is coming to Washington, D.C. to present at our annual convention. I may be able to get her to bring, at that time, a lot of materials. What time frame do you have relative to that? If you need it sooner-- This would be around the end of October. If you need it sooner, I can contact them.

ASSEMBLYWOMAN VANDERVALK: The sooner the better.

MS. BENSON: The sooner the better?

ASSEMBLYWOMAN QUIGLEY: That might be--

MS. BENSON: Then I will contact her immediately.

ASSEMBLYWOMAN QUIGLEY: That might be a little on the late side.

MS. BENSON: Just anecdotal-- I had taken an opportunity, on my own and at my own expense, to take a period of time where I went to the Touch Institute and volunteered my time as a massage therapist. I worked there for 10 days and worked day and night -- morning, noon, and night, in every area you can possibly imagine, from the burn unit in the hospital where I had my patients every morning, to attention deficit, diabetes, ADD, the list goes on and on and I can -- preterm babies, pediatric units. I had hands-on-- I was part of the research that is presently being done. Again, the studies have already been published relative to this, both with NIH and AMTA funded and with Dr. Field.

ASSEMBLYWOMAN QUIGLEY: Well, we'll look forward to hearing more from you.

MS. BENSON: And do I address them to-- Who do I send the materials to, Charlotte or to Dave?

ASSEMBLYWOMAN VANDERVALK: Do you still have the-- Actually, you could send it to me.

MR. PRICE, (Commission Secretary): Or else to the letterhead on the witness list.

ASSEMBLYWOMAN VANDERVALK: Do you still have your invitation or-- Do you have a copy of the witness list or the invitation you received for--

MS. BENSON: I have just what was given to me.

ASSEMBLYWOMAN VANDERVALK: That address on the letterhead would be helpful.

MS. BENSON: I will make sure-- Do I need 25 copies of each or will you be making copies?

MR. PRICE: One. We can make copies.

MS. BENSON: That's okay?

ASSEMBLYWOMAN VANDERVALK: Yes.

DR. AISNER: Ms. Benson, are there any studies that demonstrate the efficacy of massage in any particular chronic pain syndromes?

MS. BENSON: Do you mean fatigue?

DR. AISNER: You mentioned burn but--

MS. BENSON: Chronic fatigue syndrome was going on at the time I made my trip. I have not, in fact, seen that personally. I wouldn't want

to speak on it. I also, like this other gentleman, would prefer to leave it to the experts in that field. I can certainly, as part of the material I am asking for -- if she has completed that study or has any materials regarding that, I can have her give me those too.

DR. AISNER: One last question. I have recently seen individuals who combine massage with Chin Chin Jujitsu (phonetic spelling). I want to know if you have a comment as to whether those combined modalities might have any additional value?

MS. BENSON: I am glad you asked me that question because I love to see things combined. I think that when you treat on many levels -- a person -- and you don't just try to use one modality or one methodology to cure all ills, I think you're much better off. From the point of view-- Even with -- specifically with what you're talking about even with chiropractic, with physical therapists, with physicians or whatever, I am finding that they all work very well together when they are given the opportunity to do so. It's just that one has to be open to those things. Their consciousness has to rise a little bit. I think we are on our way.

DR. AISNER: Thank you.

MS. BENSON: You're welcome.

DR. KRAUSER: I would just like to comment further on what Assemblywoman Quigley said. As a physician who believes in massage and believes in the benefits of it, it is very frustrating for me to recommend it to somebody and have them not be able to pay for it because the insurance doesn't cover it. I strongly believe it cuts down on the use of narcotic medication. I think it improves well-being and probably improves the onset

of chronic disabilities in people who have musculoskeletal imbalances. I really would encourage you to get information on it so that we can put that forth in some of our recommendations here.

MS. BENSON: That is absolutely not a problem, because the information out there absolutely abounds. It is there. The research and the findings are done. It is published. It is available. So, all we have to do is gather it for you.

DR. KRAUSER: And I am very sorry that they don't -- that the nurses don't use it in the hospitals anymore. The situation is such that there is no time or no compensation in hospitals.

MS. BENSON: There is so much required of them that -- well, then there are massage therapists and we'll help them out.

ASSEMBLYWOMAN VANDERVALK: Dr. Aisner?

DR. AISNER: Since you made comment to the NIH Office of Alternative Therapy, and there has been some recent reports of their activities as well as their productivity, I am wondering if you may be able to link this with any of those reports, because according to those reports, out of all their granting processes, there have been only seven abstracts published? As far as I know, none of them mentioned massage therapy. There have been two that have gone forward to peer-reviewed journals. Other than that, there has been no publication or tract -- written publication out of that granting activity. I wonder if you would--

MS. BENSON: Specific to massage? Do you mean specific--

DR. AISNER: Well, since you are talking about massage, and since you mentioned the Office of Alternative Therapy --

MS. BENSON: Right.

DR. AISNER: -- whether you could reference those back to any of the granting processes?

MS. BENSON: Well, can I get that material for you? I can tell you that I had it off of the-- The last time I took NIH's, specifically, off of the Internet was probably a year and a half ago.

DR. AISNER: No. There's no question that there was probably granting in this arena. The point is that, in terms of their reporting, they have, as far as I know, not reported anything in this arena -- either in abstract or written form.

MS. BENSON: Well, let me see what I can find out. I will certainly do my best.

ASSEMBLYWOMAN VANDERVALK: Thank you very much.

MS. BENSON: You're very welcome.

ASSEMBLYWOMAN VANDERVALK: Tania Munk.

**TANIA MUNK:** Good evening. My name is Tania Munk, and I am a support group leader for fibromyalgia, from which I suffer. I appreciate the opportunity to come before you this evening. I know that the purpose of this testimony is to give you my feelings of changes that I think are needed in several areas. But in order to do that, I need to give you some background in forming my thoughts.

Eight and a half years ago, I was involved in a motor vehicle accident, which has left me in chronic pain. Mine is not life threatening, but it is enormously disabling and has changed my life. The obstacles of bureaucracy, on top of the physical and emotional adjustments that I have had

to make over the years, have been frustrating at best, and it is what brings me here tonight.

I will be addressing the issues of education of physicians, alternative and holistic treatments with insurance coverage, mental and emotional health, and auto insurance.

My diagnosis is fibromyalgia with chronic fatigue and TMJ. This diagnosis was given to me by a specialist in Philadelphia after I had cervical spine surgery. The reason I had to go into Philadelphia was because no one in my community could diagnose me, not even the specialist. I was being told that there was nothing wrong with me, or that I had rheumatoid arthritis, even though the tests came back negatively, and that no doctor should tell me that I have fibromyalgia. I feel that the doctors of this state need to be informed and educated about chronic pain and its subsequent problems that go with it, such as depression and the need for medication.

This experience is not only mine, but because I am listed as a person to contact in New Jersey for this condition by the two most prominent fibromyalgia organizations, I receive many calls from people all over this state. And by the time they call me, the people are usually in tears, and I get to hear the horror stories that they have endured, including needless surgeries because the physicians in this state were not, and some are still not, up to speed on some of these newer conditions that involve chronic pain.

The second thing I feel needs to be addressed is the holistic approach, which includes alternative medicine that is now becoming mainstream. From my own experience, it has helped me reduce the amount of medication that I need to take so that when I do need to take some, it has

a chance to work. The problem here is that the insurance companies, in particular managed care companies, do not want, nor for the most part do they cover these treatments. They would rather the patient be taking medication, getting repeated referrals, and adding to the frustration of having to live with a chronic condition. How can we hope to help someone suffering if they have to not only battle their pain but the insurance companies as well? It takes an enormous amount of energy.

Thirdly, I feel that mental health needs to be improved and more readily available to the patient who suffers from any kind of chronic pain, because along with the pain comes depression. The depression comes from the loss of one's health, and one needs to have the help to go through the five stages of grieving and healing in order not to overload the family who may be trying to be supportive, but also gets stressed and tired from living with the person who is suffering.

It is unfortunate, but there have already been two assisted suicides by Dr. Kevorkian for this condition. At least one person that I know of shot themselves in an attempted suicide -- fortunately surviving -- and had to be hospitalized for the severe depression that stemmed from the unrelenting pain. And just recently, a 46 year old Army Rabbi supposedly overdosed herself with medication for her chronic fatigue and died, according to her obituary in the *New York Times*. How many more tragedies do we have to hear about before we do something constructive to help people in chronic pain?

Last, the auto insurance industry needs an overhaul. I can only use myself as an example of someone who, after eight years, has not been able to settle the litigation after obtaining the help of the Governor herself and Lisa

Randall, the former Commissioner of Insurance and Banking. They came back to me and said that their hands are tied because of the way in which the insurance laws are written. In the meantime, my bills do not get paid for years on end until we do an arbitration, and I keep getting sent to these independent medical exams in order for them to write that there is nothing wrong with me, when clearly they see that there is, since I not only use a cane, but now have to use a walker with a seat on it because I can no longer stand. If they don't say that there is nothing wrong with me, or short of that in order not to be totally false, then they would not be taken back by the insurance company, and there goes some of their livelihood.

The pathos is that the insurance company, in wanting to send me to these doctors, have sometimes wanted to send me out of my county. And knowing that I did not legally have to oblige them, they sent me a car service. The first time the insurance company sent me a car, from Cherry Hill to Freehold, to take me to Burlington Memorial Hospital for a 20-minute exam, then drove me back to Freehold to go back to home base of Cherry Hill. The trip alone takes one hour each way. They did the same thing in sending me to Toms River, a 45-minute drive each way. By the time that they pay the cost of the car service, in addition to what they pay for the exam, they could be paying for my medical bills. After eight years and being on Social Security Disability and now being accepted at UMDNJ to be on their chronic fatigue study sponsored by NIH funding, what more do they need to know?

These delaying tactics and harassments are unnecessary, very upsetting, and I shouldn't have to keep calling my attorney to tell him to call a collection agency or ask a doctor to be a patient until we can go for an

arbitration, which goes through such legal maneuvering that it can be at least half a year after the IME before we get to have a meeting.

I understand that there is fraud, but if, after eight years, the insurance company knows that the chronic pain is legitimate, I feel that the insurance company should pay the medical bills connected to the auto accidents just as health insurance pays for our regular exams, and not put people into a situation where they are being subjected to additional stress, something that they can ill afford since it can exasperate the severity of the chronic pain condition with which they live.

I read an article in the *Star-Ledger* that the acting insurance commissioner wants to cut back in the treatment of the patient who is recovering from their auto accident to be in line with the auto insurance reform. They want to limit the costs, in general, and not cover some of the alternative methods such as reflexology, which can help the person in chronic pain. How long can or will the insurance companies try and play God and override what a physician may feel is appropriate treatment? Unfortunately, this question also applies to the managed care companies.

The term chronic pain means just that -- chronic. It may wax and wane, but one is never pain free, and they may need ongoing treatment for the rest of their life. Are the insurance companies prepared for the ramifications of denying the patient coverage? I sincerely hope not.

It is my hope that by the end of these hearings, the Commission will see that some definite changes need to be made within the medical and mental professions and the insurance companies. Somehow, there has to be a way to work as a unit between doctor, patient, insurance company, the State,

and ultimately the nation as a whole, without it becoming a constant battle of the patient trying to constantly justify the existence of their pain to a physician who may not have up-to-date knowledge, or a physician trying to get the patient the necessary help and treatment, be that medically, mentally, holistically, or whatever the physician feels is appropriate, and an insurance company limiting the amount of care needed because of the bottom-line mentality and profit.

It would be in the best interest of the patient and ultimately the insurance companies if there is greater latitude in the form of treatments they can receive. It will benefit the patient in being able to have a better quality of life to whatever degree that may be possible, and it will save the insurance company money by not having to pay for constant tests and possibly reduce the amount of medication the patient may need to take.

In the end, my recommendations are to educate the medical and mental professions in the complexities of chronic pain; to be more open to the holistic forms of treatment for these conditions; to include mental health as part of the treatment stemming from the depression that comes with living in constant pain; to invite the insurance companies to change the way in which they view the patient and pay for the cost of the treatments in all forms in order to, hopefully, reduce the amounts of time needed for testing and for the amount of medication the patient takes to ease the pain.

I will be happy to answer any questions.

ASSEMBLYWOMAN VANDERVALK: I don't see any questions, but don't take that to mean that we weren't listening.

Thank you. I appreciate it.

We don't have anyone else signed up -- or signed up in advance, I should say -- but I think there are some people here that do wish to testify and may have signed up at the front desk.

MR. PRICE: There are forms on the chair -- on one of the chairs behind the audience, if anybody would like to testify. We would encourage you to fill out one of those forms and bring it up if you haven't already reserved a--

ASSEMBLYWOMAN VANDERVALK: Is there anyone here that wishes to testify. (affirmative response from audience)

Please join us.

Have you filled out one of those forms?

**GAIL M. FERGUSON:** No, but I will.

ASSEMBLYWOMAN VANDERVALK: Okay. We just want that for the record.

MS. FERGUSON: Absolutely.

My name is Gail Ferguson, and I am also a patient with fibromyalgia, chronic fatigue, and chronic pain. I think that what we need to look at with this Commission is who is going to advocate for the patient with these insurance companies. When are they going to start realizing that people in chronic pain should not be as limited as they are now, with the amount of treatment you can receive? I personally go to California at least once a year to get some treatments that New Jersey doesn't allow.

ASSEMBLYWOMAN VANDERVALK: Excuse me for interrupting, but would you like to elaborate on that?

MS. FERGUSON: I have a doctor that I was referred to in California, who is a highly respected physician that has studied fibromyalgia and has written books about the disorder. He works on the premise that fibromyalgia has to do with a chemical imbalance in the brain. He has developed a protocol that he uses with various medication therapies that he has thoroughly researched to find the right combination for the patient.

When I returned from California, one of the medications that was prescribed for me that really made a 180-degree turn in my life, my doctor in New Jersey was not able to prescribe. I would have had to see a psychiatrist and be classified with a certain disorder in order to have that medication prescribed to me in New Jersey. So, I had to have my doctor in California send me a written prescription every month.

People in chronic pain, especially with the disorder that I deal with and that Tania deals with as well, and the chronic fatigue, also need to have alternative therapies. I have exhausted my lifetime limit for physical therapy, which was very helpful to me, and now, unless I pay for it myself for the rest of my life, I cannot receive any physical therapy for this disorder.

The managed care companies are being managed by bottom line. The managed care companies do not know the patient. They have never seen the patient. In most cases, they don't even have a complete record of the patient's condition. I even had my managed care company call me to ask had I really made all those office visits to my doctor. They were investigating him for fraud. I was so incensed, because they didn't even know what my diagnosis meant when they called me on the phone. I subsequently wrote them a letter, and my doctor, as a matter of fact, received an apology from them. It just goes

to show that with chronic pain, you don't have a lot of alternatives. I am, fortunately, able to take a minimum of medication right now, but I need pain medication to go to sleep every night. I cannot sleep through the night without my pain medication.

With the reforms that we're talking about for auto insurance-- It's frightening, some of the limits that they propose to put on the treatment of an accident victim. If someone with my disorder were to have an automobile accident, even a minor one, the muscle pain that we endure on a daily basis would probably flare up into a major flare and require a good deal of treatment that we probably won't get under the proposed rules.

I urge you to look towards some sort of recommendation for people in chronic pain -- for the managed care organizations. They don't seem to want to respond to the patient. They only want to respond to "Okay, this is what you have." And the physicians themselves have such a battle with these managed care companies, having to add extra staff just to deal with the peculiarities of different managed care organizations, different plans within the same managed care organization, the number of referrals you have to get. I personally have probably three major bills, going back three years, that have not yet been paid. I have been threatened to be sued. I have collection agencies calling me constantly. It's just an intolerable situation for people in chronic pain.

I would urge you to look at the insurers to formulate some sort of policy through which the managed care organizations would have to provide a certain level of care for people with chronic pain. Again, people with fibromyalgia don't look sick. There is no magic blood test. There is no x-ray,

there is no MRI or scan that is going to show that a patient has fibromyalgia. It's a very complex diagnosis. As Tania said, most of us have been through many physicians, and we have been told that we are just crazy, that it is all in our heads, and various things like that. To try to get a managed care organization to continue with your care when they can't find a solid diagnostic test to say that this person does need this, it's very difficult.

So, I thank you for your time. I hope that you will make those considerations when you make your recommendations.

ASSEMBLYWOMAN VANDERVALK: Thank you. Let me assure you that we are looking at the auto insurance aspect of it, because Dr. Ashendorf had brought that to our attention very rapidly. He is really concentrating on that.

MS. FERGUSON: Thank you.

ASSEMBLYWOMAN VANDERVALK: Thank you.

MS. MUNK: Can I just add something.

ASSEMBLYWOMAN VANDERVALK: Certainly. Why don't you just stay where you are.

MS. MUNK: Okay, thanks.

ASSEMBLYWOMAN VANDERVALK: Oh. I am sorry. If it is a problem, maybe somebody can carry a microphone over to you.

MS. MUNK: No, I can come up.

Dr. Ashendorf, you asked before -- or somebody asked before about massage therapy, and whether it really does help. I would like to tell you that it really does. What I have seen happen to myself is-- I have gone to mostly all holistic helpers, and a lot of them I am paying out of my own

pocket, such as massage therapy and reflexology. It has reduced the amount of medication I have to take. I am able to go to my chiropractor, who does what is called kinesiology. Obviously I see that the doctor knows what I am talking about here. I take vitamins, kava-kava, to help me sleep through the night. It does reduce the amount of medication -- also acupuncture.

As far as the bills go, I have just received an acupuncture bill, which is outstanding for my auto insurance, of \$4000. That's just the acupuncturist. My chiropractor's bill is at least \$15,000. I have been sent to three IMEs, and I don't know what the reports are, because they are refusing to send the reports in to my attorney. I can't wait forever. I am asking for an arbitration. I haven't had one bill paid in the past four years. This goes on and on. Every time I go to an arbitration and I get it paid, they stop paying again.

It is absolutely ludicrous. If I weren't at the point where I say put me in a collection agency, I am giving it all to my attorney, I could be in major flares. I have had to learn how to cope with the bureaucracy through which they are putting me to get the stuff done that needs to get done.

It is unbelievable what you have to do to live with this chronic pain. When you have had a car accident, good luck. Eight and a half years later I am still sitting here, and my bills aren't getting paid. I don't even see the sight of a settlement. They know that I am permanently disabled. I just hope that when this Commission finishes the hearings, we will have some form of legislation that will help not only those who suffer with the fibromyalgia and chronic fatigue, which is a larger population than you would like to know at

this point, but other chronic problems as well. We are battling not only our pain, but the insurance companies and the doctors as well.

I thank you for your time.

ASSEMBLYWOMAN VANDERVALK: Thank you.

Is there anyone else in the audience that wishes to testify? (no response) Last call.

Well, thank you very much. We appreciate it.

The members of the Commission will be meeting for a few minutes now.

Thank you.

**(HEARING CONCLUDED)**