MINUTES OF THE MEETING OF THE ASSEMBLY COMMITTEE ON HEALTH AND HUMAN SERVICES

Seventy-Fifth Session February 18, 2009

The Committee on Health and Human Services was called to order by Chair Debbie Smith at 1:37 p.m. on Wednesday, February 18, 2009, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4401 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Copies of the minutes, including the Agenda (Exhibit A), the Attendance Roster (Exhibit B), and other substantive exhibits, are available and on file in the Research Library of the Legislative Counsel Bureau and on the Nevada Legislature's website at www.leg.state.nv.us/75th2009/committees/. In addition, copies of the audio record may be purchased through the Legislative Counsel Bureau's Publications Office (email: publications@lcb.state.nv.us; telephone: 775-684-6835).

COMMITTEE MEMBERS PRESENT:

Assemblywoman Debbie Smith, Chairwoman Assemblywoman Peggy Pierce, Vice Chair Assemblyman Ty Cobb Assemblyman Mo Denis Assemblyman Joseph (Joe) P. Hardy Assemblywoman Sheila Leslie Assemblywoman April Mastroluca Assemblywoman Bonnie Parnell Assemblywoman Ellen B. Spiegel Assemblyman Lynn D. Stewart

COMMITTEE MEMBERS ABSENT:

Assemblyman John Hambrick (excused)

STAFF MEMBERS PRESENT:

Amber Joiner, Committee Policy Analyst Darlene Rubin, Committee Secretary Chris Kanowitz, Committee Secretary



Minutes ID: 255

Olivia Lloyd, Committee Assistant

OTHERS PRESENT:

- Richard Whitley, Administrator, Health Division, Department of Health and Human Services
- Mary Wherry, Deputy Administrator, Health Division, Department of Health and Human Services
- Lawrence Sands, D.O., M.P.H., Chief Health Officer, Southern Nevada Health District, Las Vegas, Nevada
- Brian Labus, MPH, Senior Epidemiologist, Southern Nevada Health District, Las Vegas, Nevada
- Darla Leibel-Burrow, Executive Director, Nevada Hepatitis C Task Force, Reno, Nevada
- Ken Morgan, Member, Nevada Hepatitis C Task Force, Reno, Nevada
- Tom Ruble, Member, Nevada Hepatitis C Task Force, Reno, Nevada
- Alex Lapasaran, Nurse Practitioner, Digestive Health Associates; Member, Nevada Hepatitis C Task Force, Reno, Nevada
- Shawna Jones, Nurse, Nevada Hepatitis C Task Force, Reno, Nevada
- Sandy Curl, Director, Sierra Nevada Hepatitis C Support Group, Carson City, Nevada; Nevada Hepatitis C Task Force, Reno, Nevada
- Mark A. Barry, M.D., Desert Orthopaedic Center, Las Vegas, Nevada
- Edwin Suarez, Physical Therapist, CEO/President, Physical Therapy, LLC, Las Vegas, Nevada
- Leann Sparks, Physical Therapist, Home Health Care; Vice President, Nevada Physical Therapy Associates, Henderson, Nevada
- Robyn Kaiser, Occupational Therapist, Director, "Sense"ational Kids, Las Vegas, Nevada

Chairwoman Smith:

[Roll called. Opening remarks.] We have four presentations on the agenda today. Three presentations relate to infection control in the Hepatitis C exposure, and one is related to Medicaid cuts for certain physicians. We are going to Las Vegas for hearings on Saturday, February 21, regarding the Hepatitis C issue.

I thought it would be helpful today if we had an overview of the issues surrounding the Hepatitis C exposure and an update, so that we all go into the hearing on Saturday ready to hear our first bill. In addition, we have the presentation from some physicians who were here this morning to appear before the Joint Ways and Means and Senate Finance Committee. I thought it would be appropriate for them to come before this Committee this afternoon while

they were in town and testify in person. We will hear that presentation at the end of the agenda.

Before we start with the presentations, I need to return to one matter from a previous meeting. During the February 16 meeting, I referred <u>Assembly Bill 83</u> to a Subcommittee that will be chaired by Assemblywoman Pierce. I would like to also refer <u>Assembly Bill 76</u>, the other bill that we heard on February 16, to the same Subcommittee. Both of those bills were sponsored by the Division of Child and Family Services (DCFS) and relate to similar issues regarding the protection of children. While the issues around <u>A.B. 76</u> were not as complex or as many, I thought we could probably deal with both bills together and come back to the Committee with recommendations on both bills.

Richard Whitley, Administrator, Health Division, Department of Health and Human Services:

I will be speaking about health care associated infections and more specifically the Hepatitis C outbreak associated with the Ambulatory Surgical Centers (ASC). I have provided a handout, "Infection Control Practices in Nevada" (Exhibit C). This presentation is also available on the Nevada State Health Division's website www.health.nv.gov.

I would like to begin with a framework for licensure and certification of health facilities. Facility regulation is currently made up of federal, state, and local authority with an optional overlay of national accrediting bodies. On page 6 (Exhibit C), it shows the frequency with which the health facilities are surveyed. Currently, the only facility type required in state statute to be inspected with a frequency is group homes, also referred to as "assisted living facilities." The statute requires that they be inspected every year. In regulations, homes for individual residential care are inspected every three years. Note that there is currently no statutory requirement for inspecting ASCs with any periodicity.

On page 7 (Exhibit C), the frequency for inspection for all other facility types is determined by the Centers for Medicare and Medicaid Services (CMS). The CMS contracts with the State Health Division to provide inspections. The contract sets priorities. The CMS put their priorities in tiers, for example, ASCs are in tier 4 which is CMS's lowest priority for the state to inspect. National accrediting bodies also play a role in the inspection process. In the case of ASCs, CMS has delegated the opportunity for inspection authority to the national accrediting bodies. The accrediting body matrix on page 18 shows the entities that are currently authorized by CMS to accredit health facilities, and, therefore, the responsibility for inspecting these facilities for the purpose of Medicare falls to the accrediting bodies. The intent of this collective oversight is to insure patient safety and improve quality of care.

I will now focus specifically on the Hepatitis C outbreak associated with the ASCs, how the system worked, and how, in some ways, it failed. On page 20 is the Centers for Disease Control (CDC) Report on Hepatitis C and how it was linked to the Endoscopy Center of Southern Nevada. It is important to note that Southern Nevada Health District's (SNHD) epidemiology staff investigated and identified issues with Hepatitis C and linked the patients to the Endoscopy Center. The disease identification and investigation part of the health care system did work. Dr. Sands and Brian Labus will be speaking after me on the specifics of the investigation.

Most medical errors are a result of system failure, as a result of an individual's failure, an organization's failure, or failure between organizations. On the chart on page 32, one can see the complexity of the system. In responding to the Hepatitis C outbreak, we needed to recognize all of the agencies and organizations that collectively comprise the health care system. It is important to note that no single entity or agency oversees this entire network. In addressing the Hepatitis C outbreak, one of the things that we identified was the disconnect between many of the organizations.

Page 33 illustrates the issues or challenges the Health Division identified in our role of regulating facilities. Pages 34 and 35 show how the Health Division has or is responding to the need for change. This is either through statute with a bill draft request (BDR), or through regulation, or through policies and procedures within the organization. The Health Division, for example, has partnered with Southern Nevada Area Health Education Centers (SNAHEC) to develop an internet-based standard infection control curriculum based on the CDC guidelines. The curriculum is posted on SNAHEC's website at www.snahec.org. Additionally, the Health Division has established memorandums of agreement with accrediting bodies so that we can improve the communication when the accrediting body does an inspection and identifies an We can also reciprocate and provide information to them when we respond to a complaint and identify an issue.

There were many issues within the organization that needed to be improved, and there are many issues between organizations that can be improved. For example, we did not have a full complement of facility surveyors. Historically, we ran a vacancy rate of about 20 or 25 percent. We aggressively recruited to fill all positions, and those continue to remain filled after more than six months. It is interesting to note that the need for inspection of our facilities was brought to our attention by employees—nurses, primarily—who had an interest in working in this field, and they identified gaps in the health care system. That positive outcome was one where the employees not only discovered the problem but they were also the solution.

On an external level, from an agency perspective, the relationship between the licensing boards is a challenge both in informing them and communicating with them, related to the health professionals that they license. Each has its own process. The matrix on page 36 was created as a tool to assist our surveyor staff with communicating and navigating the complex system that is required for notifying and making a complaint. This is difficult for us as a state agency, and I understand, from talking to consumers, that it is more difficult for them to navigate this same process. The matrix led us to try to work with all the licensing boards and meet with them to determine a better way of communicating. We have had a great deal of success. The Board of Medical Examiners' Executive Director, Louis Ling, within the first two weeks of his leadership, had set up a meeting with Marla McDade Williams, the chief of the Bureau of Health Care Quality and Compliance, and me, and clearly established that he wanted to work with us when we identified a problem in a facility, when we needed to report a physician, and when the opportunity arose for joint inspections or investigations.

I would also like to highlight the Nursing Board. Throughout this process the Nursing Board was easy to work with, and there have been improvements with the communication between the boards. Before the Hepatitis C outbreak, many of these communications were individually-based because an individual staff member had an existing relationship, but there was no systemic or organizational structure in place allowing for this communication to be standardized. We have changed that. Now, inspectors in the Health Division have embedded in their work performance standards the obligation to report to the various boards so that communication across the system is assured.

The flow chart on page 39 illustrates an algorithm that we have created to show how a patient can navigate the system when making a complaint. This complaint process may be accessed by going to the Health Division's website, www.health.nv.gov, and clicking on "Complaint Forms, Instructions and Patient Safety Guide." While we could not achieve a universal complaint form, we did hear consumers voice their frustration with the complaint process, and we were at least able to make navigating through the process easier.

There is a saying that our regulatory staff use and that is, "When you look, you find." Page 64 illustrates that of the approximately 50 ASCs inspected during the past year, 49 percent had deficiencies in infection control. It also shows the categories of problems identified. The examples are the reuse of a syringe in a single-dose vial to the reuse of a rubber bite block manufactured and intended for a single use. I point this out to illustrate that when we look, we do find. But the goal is to improve the quality of care, to identify issues, take corrective action, improve the health care system, and protect the public's

safety. We have put in a budget request for additional surveyors that would allow us to frequent all health care facilities in our state every 18 months. Our budget is half fee-funded or and half funded through a contract with CMS, so our budget request does not include the need for additional General Fund dollars.

In conclusion, the goal of the regulatory agency is to improve the quality of care and patient safety. It is not to find issues and shame our already limited health care system. One thing we have found since the issue with Hepatitis C became evident was that facilities now are self-reporting to us, and that is new behavior. We take that as a sign of a culture change. In the past, we would identify an issue and bring it to the attention of the facility when we inspected. What we have seen in the last three months is that facilities are proactively reporting to us when they have identified an issue.

Assemblywoman Spiegel:

Thank you for your comprehensive materials. Regarding the chart on pages 32 and 38, are you partnering with the private sector and insurance companies that handle malpractice and liability insurance? It seems to me that they would have a vested interest in making sure that the facilities and the physicians that they insure are adhering to best practices.

Richard Whitley:

This is a work in progress. No, we have not done that, and we can follow up with that idea. We have not established a requirement, either out of inquiry from the industry or on our part, to inform them. You raise a good point. Most of what we have done in regard to reporting has been through discovery of just who does need to be communicated with.

Assemblywoman Spiegel:

It seems to me that there may be a way to have the insurance companies expand the reach of some of the inspections and notifications and minimize the cost to the state while maximizing the benefit to the public at large.

Assemblyman Hardy:

I appreciated the chart on page 39 and went to the link www.health.nv.gov. I went through it, and imagine my surprise when it sent me to the Consumer Health Assistance Bureau that we are doing away with. It illustrates the ramifications from any small change. Some of us on this Committee have expressed dismay about discontinuing something that has been in place and should stay in place.

Assemblywoman Pierce:

Looking at the chart on page 6, Facility Frequency of Inspections, in column one where the ASCs are shown, the state requires an initial inspection and then one every six years thereafter. The last column, NAC/NRS, is blank, so where does that mandate come from?

Richard Whitley:

That was an attempt on the Bureau's part to fill in blanks that neither the state nor CMS had identified any periodicity. I mentioned previously that the only authority currently over ASCs is through our contract with CMS. The CMS contracts with the State Health Division to do a scope of work, and they establish priorities. Among the facility types, ASCs have the least priority. There are two bill draft requests (BDRs) that would require, in statute, the Health Division to do annual inspections of ASCs.

Assemblywoman Pierce:

What accrediting agency would inspect an ASC?

Richard Whitley:

The national accrediting bodies have the same priority set by CMS. The CMS has given them the authority to go into a facility; however, the facility would have to pay to have that national accrediting body make an inspection. We license all facilities in the state, but once a facility is certified, it can then bill Medicare. Due to the number of facilities that wanted to become certified, and the limited resources provided to the state by CMS, CMS has delegated that authority to the national accrediting bodies. One of the reasons I identified this was because we found, during the Hepatitis C crisis, that we had no formal agreements with any of the accrediting bodies to communicate with us if they responded to a complaint or, in an annual inspection, they discovered a problem. That problem could involve anything from a simple issue to actually pulling their accreditation.

We now have in place a memorandum of understanding for communication between us, going both ways, because it is also possible that we would receive a complaint and need to communicate that to the accrediting body. We are in the process of negotiating the language of the memorandum with each of the national accrediting bodies.

Assemblyman Hardy:

Do you have any information on how many ASCs have become affiliated with the national accrediting bodies since the Hepatitis C outbreak? It would be good to know that before we come out with a BDR that requires it.

Richard Whitley:

We do have that information but I do not have it with me. I will be prepared to have that information on Saturday, February 21.

Chairwoman Smith:

What is the definition of an Ambulatory Surgical Center?

Richard Whitley:

It is defined by CMS, and it is in the handout. I would not do it justice to try to define it. The CMS defines the criteria for each of the facility types. The definitions are driven by the fact that meeting established criteria enables the facilities to bill CMS for Medicare reimbursement.

Assemblywoman Parnell:

On page 43, Facts About ASCs, my confusion when I hear that term stems from the last part of the first bulleted item, which states "...providing surgical services to patients not requiring hospitalization." At the surgery center here in Carson City, one can stay up to three nights. Is there a clarification on that part of the definition?

Mary Wherry, Deputy Administrator, Health Division, Department of Health and Human Services:

I think the surgery center in Carson City may be licensed as a hospital.

Chairwoman Smith:

One of the bills that we will hear on Saturday is from your Division and directly related to this issue.

Lawrence Sands, D.O., M.P.H., Chief Health Officer, Southern Nevada Health District, Las Vegas, Nevada:

[Read from prepared statement (Exhibit D).] I appreciate the opportunity to share information with the Committee about the Southern Nevada Health District's role in the Hepatitis C investigation and its response.

What happened in Las Vegas is not unique. There have been similar outbreaks caused by similar unsafe practices in areas throughout the country including New York, Nebraska, and most recently, North Carolina. What distinguished the outbreak here in Nevada was the magnitude of patients affected. Conditions should never have existed to cause the Southern Nevada Health District (SNHD) to notify almost 60,000 that they may have been exposed to the blood of other patients by those they entrusted with their personal health and well-being.

As a physician, and as the Chief Health Officer that oversaw the notification, I can attest to the fact that the circumstances that led us to be here today were completely avoidable and betrayed the most fundamental and critical element at the core of the doctor/patient relationship: trust. The public deserves to have their trust in the health care system restored. It is unbelievable to me that after the attention these outbreaks and exposure notifications have received, these events continue to occur. It is very disturbing that in the wake of these notifications we are still learning of infection control breaches in medical facilities in other parts of the country. However, on a positive note, as Mr. Whitley has indicated, we have seen evidence here in Nevada that medical facilities are becoming more proactive and more vigilant and are even self-reporting unintentional infection control breaches, and making decisions to provide information to their patients even when there has been little risk of disease transmission.

On another positive note, I recently had the privilege of participating in the announcement of a national campaign on Capitol Hill last week on safe injection practices that will be launched in Nevada. While we all wished this type of campaign was not necessary, I am glad to be connected with this effort and look forward to working with my colleagues and the community partners here in Nevada to promote the message of "One Needle, One Syringe, and Only One Time." My ongoing involvement includes serving as a member of the Safe Injection Practices Coalition along with the Nevada State Medical Association who will lead the efforts to promote the cause in Nevada where the "One and Only Campaign" will be first piloted. We have provided the Committee with copies of the news release that includes more details of this campaign [included in (Exhibit D)]. We are also working with other public health agencies throughout the country to contribute to a tool kit that has been compiled by the National Association of City and County Health Officers (NACCHO). The NACCHO recently facilitated a meeting in Las Vegas that was attended by local and state health representatives, as well as public health officials from other states who have experienced similar outbreaks. The participants shared their best practices and are working together to compile materials that can be used by other public health agencies in the event that they find themselves in the unfortunate position of having to respond to a similar crisis.

Other activities that have occurred during the investigation or as a result of our response include the implementation of the Hepatitis C Helpline that was coordinated through the Rocky Mountain Poison Control and Drug Center. The Helpline handled more than 34,000 calls through the course of the investigation. The Health District also coordinated a Hepatitis C Community Forum that was held last April. The event included a panel of experts and

allowed the public to have their questions answered. Booths were staffed by community partners to provide information and resources to the attendees.

An additional activity related to the outbreak was the Hepatitis C Awareness Survey conducted by the University of Nevada, Las Vegas (UNLV) Cannon Survey Center (Exhibit D). The Center released its findings in May 2008, and the study found that close to 47 percent of respondents disagreed or strongly disagreed with the statement, "Patients receive high-quality medical care from the health care system." The study also found that almost 71 percent of respondents agreed or strongly agreed with the statement, "The health care system covers up its mistakes." These responses underscore the importance of our continued activities to restore faith in the health care system here in Nevada.

However, as I conclude my remarks I would like to say that a great deal of attention has been placed on a few health care providers who have put too many people at risk. We should not overlook the fact that the vast majority of health care providers in Nevada are devoted to insuring the safety of their patients, and I will continue my efforts to encourage all providers in the state to embrace the tenets of the safe injection campaign. Ultimately, it is up to each and every health care professional to regain the trust of those they serve and those who depend on them to insure the safety of their health care, and why it is important to continue to encourage patients to feel comfortable about asking questions of their physicians. Providers must take a proactive step of reassuring those they serve that their health care and safety is of the highest priority. By working together to educate both patients and health care providers we can help to insure that no more patients will ever receive a letter like the one received by the 60,000 people who were patients of the clinics associated with the Nevada outbreak.

Brian Labus, MPH, Senior Epidemiologist, Southern Nevada Health District, Las Vegas, Nevada:

[Read from his prepared statement (Exhibit E)]. For over the past year, I have been the lead public health investigator for the largest health-care-acquired Hepatitis C investigation and outbreak in United States history. I could not have done all this alone, and I come before you proudly representing hundreds of different investigators and people from multiple agencies that took part in this investigation response.

The purpose of our investigation was to determine the basic facts of the outbreak. We wanted to establish a chain of events and define the extent of the problem. We wanted to know the who, what, when, where, and how of this particular outbreak. As for why, that is beyond the scope of the public

health investigation. I will leave it to our legal system to determine the answer to that question.

Hepatitis C is a viral infection spread through blood-to-blood contact. Most people infected show no outward signs of infection and would not know they were infected unless they had a blood test. In the 10 to 15 percent of infected people who actually develop the disease, they typically develop the symptoms of jaundice, nausea, and abdominal pain within six months of their exposure to the virus. The disease cluster itself was identified on January 2, 2008, when routine physician reporting and disease investigation by the SNHD Office of Epidemiology linked three cases of acute Hepatitis C infections to the Endoscopy Center of Southern Nevada. In an average year we see about two cases for the entire county. We conducted our field investigation jointly with the CDC and Nevada State Health Division's Bureau of Licensure and Certification, now known as the Bureau of Health Care Quality and Compliance. Through the observation of clinic procedures, conversations with staff members, and review of clinic records, we identified two practices that when they occurred simultaneously led to patients potentially being exposed to the blood of other patients. We provided a handout that gives a graphic depiction of this [included in (Exhibit D)], but I will explain what happened. The transmission of disease here was a two-step process: During the injection of a sedative to a patient, blood can be drawn back up into the syringe. If that patient needed a second dose of the sedative, the needle was removed and that syringe, which was potentially contaminated with blood, was reused. In accessing the vial, the contaminated syringe could transfer blood into the medication. The now-contaminated vial, which was labeled "for use only on a single patient," was then used for additional patients. This blood would not have been visible to the naked eye but could contain enough virus particles to transmit disease from patient to patient.

During the investigation, we considered a number of other means of transmission as well. We did not identify other practices that would have placed patients at the risk of infection. All staff members tested negative for infection with Hepatitis C. Infected patients did not all have procedures performed with the same scope, nor did they necessarily have the same type of scope used. The scopes appeared to be cleaned and disinfected properly. We did not identify any significant infection problems with the placement of the IVs, and there was no evidence of foul play or intentional transmission. The injection safety issues identified at the clinic were not a one-time occurrence or an accident. In fact, clinic staff stated that they had been instructed to reuse syringes and vials as a routine practice, and we determined that these unsafe injection practices had been occurring for nearly four years. Most infected patients would not know they were infected without being

tested. Therefore, on February 27, 2008, the SNHD began the largest public health notification in history, notifying 50,000 patients of the Endoscopy Center of Southern Nevada of their exposure risk, and recommended that they be tested for Hepatitis C as well as for two other blood-borne pathogens, Hepatitis B and HIV. In June, this notification was expanded to include an additional 13,000 patients from the Desert Shadow Endoscopy Center which was owned and operated by the same management as the clinic. At this clinic, Bureau of Licensure and Certification inspectors identified the vials for multiple patients even after the problem had been identified at the first clinic and staff was trained in proper injection safety. In addition, an acute case of disease was identified in a patient of the clinic from June 2006, who, two days prior to undergoing his procedures, had tested negative as part of routine laboratory testing.

Our field investigation answered the questions of what, when, where, and how, In other words, how many patients were infected which left us with who? during their procedures at the clinic? To answer this question, we needed to know three things: First, who had a procedure and when did they have it? Second, who was infected? Third, where did that person get infected? Identifying the patients at the clinic proved to be a significant challenge. The list of patient names provided by the clinic to Southern Nevada Health District was missing vital information, such as the procedure dates and dates of birth. In addition, and more importantly, it was missing about 10,000 names. This led to the second major challenge; determining who was infected. Tens of thousands of people began the testing process through local commercial laboratories. Without birth dates, it was not possible to link the list of patients who were being tested to the list of people provided by the clinic. This problem was compounded by the fact that not just former clinic patients were being tested but so were the contacts of patients, people who were undergoing treatment in management of their routine Hepatitis C disease, and people who decided for some other reason they wanted to get tested for Hepatitis C. Without the ability to link the different sources of information, contacting patients for follow-up became nearly impossible.

The third challenge we faced was in determining where people were infected. Laboratory tests can tell us if a person is infected, but they cannot tell us when that infection occurred. If a patient knew they were infected before they ever set foot in the clinic, we could clearly say that the infection was unrelated. For an acute case of disease, we know that the infection occurred within six months prior to the onset of symptoms. However, for the vast majority of patients, those without acute disease, we had to evaluate the patient's lifetime risk for infection. If a patient reported one of the six major risk factors for Hepatitis C infection, we could not make a determination about where their

infection actually came from. For the remaining patients, the question we had to answer was: How closely can we relate the infection to their procedure? For the days of known disease transmission, we attempted to obtain blood specimens from all patients who were seen on those particular days. Through genetic testing we were able to identify a source patient on both days of known transmission. Clinic records indicated that the source patients knew of their positive infection status and reported this to clinic staff members in the pre-procedure assessments.

From the July 25, 2007, patients, we identified one acutely-infected patient whose viral strain was a 98.6 percent genetic match to the source patient. From the September 21, 2007, patients, we identified six cases, which is an infection rate of about 10 percent of that day's patients. The five acute cases and one non-acute case were between a 99.3 percent and 100 percent genetic We identified two additional acute clinic match to the source patients. associated cases that were diagnosed in 2005 and 2006, but were not reported at the time. Genetic testing was not performed on these cases as the purpose of testing is to compare different strains and is not meaningful for isolated cases or where we do not have potential source cases. Through multiple investigative methods, including the implementation of a patient registry that had received over 7,500 enrollment forms, we have identified a total of 114 cases to date between the two clinics. Nine of these cases had acute disease or were genetically matched to the source patients, and the remaining 105 cases reported no significant risk factors and no positive test prior to their procedures. There have been no cases of Hepatitis B or HIV linked to the clinic.

Given the number of significant limitations in our ability to identify infected patients, the true magnitude of disease transmission related to unsafe injection practices at the Endoscopy Center of Southern Nevada will never be known. A recent review by CDC of 33 health-care-associated Hepatitis outbreaks since 1999, including this outbreak, showed that not only was our notification of nearly 63,000 patients larger than any other conducted, it was larger than all of the other notifications combined. Nevada has the dubious distinction of having not only the largest public health notification of its kind in United States history, but of having the largest outbreak of health-care-associated Hepatitis C in United States history as well. Unfortunately, the circumstances of this outbreak we investigated were not unique. Many outbreaks due to unsafe injection practices have occurred throughout the country over the past few years, and, most disturbingly, several have been reported in other states after our outbreak became public.

In closing, I would like to thank the thousands of health care providers, educators, regulators, public health professionals, elected officials, family

members, and friends who have supported us, and more importantly, supported the exposed and infected patients over the last year. It is my sincere belief that through our sustained efforts we will not be thought of as the state with the largest outbreak, but that Nevada will be thought of as the national leader in patient safety.

Chairwoman Smith:

That was very helpful. How long did it take from the time a patient was diagnosed with Hepatitis C until a connection was made and you knew that this investigation had to be opened?

Brian Labus:

We identified three cases that made up that cluster. The first case got reported within several days of that initial diagnosis. It was reported by the physician, and we contacted the person and did our investigation. At that point we just had one case. We identified a second case on December 28, and we were able to finish our investigation and show that we had two patients with procedures on different dates. On January 2, as we started looking at the connection between those two cases, we identified the third case. We were able to interview the case on that day and find out that the patient also had a procedure on September 21. The process, from the identification of the disease to its being reported to us, was rather quick, within a matter of days, and then it was just a matter of how quickly we could contact that person and complete the interview.

Chairwoman Smith:

So it was really very quick because it soon became public, and the investigation started in January. How did you determine the timeline of identification? Was it a four-year period that you used?

Brian Labus:

The starting date we chose was March 2004. We selected that date because at that time the clinic had undergone a significant renovation, changed their practices, and expanded from a one-room to a two-room practice. They changed the way they did business on a day-to-day basis. We cannot say that those practices did not happen prior to that, but there was no way for us to make that evaluation as we were really looking at a new business. The final date of January 11 was decided upon because that is when we saw them reuse the syringe, that is when we pointed out the problem, and that is when they corrected that practice.

Chairwoman Smith:

What is the incubation period for Hepatitis C when one has been tested and found to be clear?

Brian Labus:

People should test positive for infection with Hepatitis C within six months of exposure. After they pass that six month window they can be assured they are not infected with Hepatitis C. In this particular outbreak, that was a challenge because we had patients who were potentially exposed at the beginning of January, we were letting them know at the end of February, and they still had to wait four more months to be able to be tested. Those were some very anxious months for a lot of people, even if they had tested negative, as they were not sure that it was truly the case.

Chairwoman Smith:

With the volume of patients that these clinics had, it would seem to me that one of the pharmaceutical companies might have noticed if the clinics were reusing the vials. Was that ever part of the discussion?

Brian Labus:

No, it was not, because the pharmaceutical company would have no way of knowing what that patient volume was. They only knew how many vials were ordered, and they were not responsible for determining how those vials were used or what the appropriate number was.

Chairwoman Smith:

Are those clinics now closed?

Brian Labus:

Yes. They were closed primarily through business licensing in different jurisdictions, after the outbreak was announced.

Chairwoman Smith:

Who is in control of the clinics' patient records now?

Brian Labus:

All the records have been turned over by law enforcement to representatives of the clinic. The clinic has a website where patients can download a form to request copies of their records. They have opened an office to deal with all of those record requests.

Chairwoman Smith:

What do you feel were your biggest obstacles when this first happened and the investigation began?

Brian Labus:

Our biggest challenge was having partial information and trying to link things together. Even if we had the legal authority to require that certain documents be provided to us, the documents did not have some of the information we needed. For example, the procedure room that the patient was actually in was not recorded on the chart. There was a lot of information that was recorded incorrectly or inaccurately in those charts. From the legal issues standpoint, one of the major hurdles was communication with other agencies. We were allowed to share some information with some agencies, but not with other agencies, and for us, this was the first time we had dealt with a situation like this. It was a major challenge even trying to determining who our partners were.

When it comes to our investigative authority, we have a broad general power to do those investigations, but we do not have that specific statutory authority that allows us to subpoena records from the clinic. We walked in, asked the clinic to provide the documents, and they cooperated. Had they refused to cooperate in our investigation, it would have been a very different story, because it would have been very difficult to get access to any information we needed.

Chairwoman Smith:

We have heard a lot lately about possible money from the stimulus package to help with electronic medical records. Would that have improved your situation if we had had more information being recorded electronically?

Brian Labus:

One of the problems we had was that a lot of information was recorded incorrectly, and I do not think it matters how it was recorded if what is recorded is incorrect. I have talked with investigators who have worked in situations where they had electronic medical records, and in some cases it really does not make things any easier. Sometimes it is just a scan of something handwritten. It really depends on the format of those records. The potential is there for medical records in electronic format to help our investigations, but because of all the variables the problem with those records is inaccurate information is entered.

Assemblyman Hardy:

Did you bring that printout with you?

Chairwoman Smith:

Yes, we have it, Hepatitis C Outbreak and Response Update (Exhibit E).

Assemblyman Hardy:

You mentioned two days and used the word "patient." Was there one single patient who was the source patient?

Brian Labus:

Yes, we identified one patient on each day who was the source patient for subsequent transmission that day. On July 25 we had one source patient whose blood infected a second patient. On September 21 we had one source patient whose blood infected six other patients.

Assemblyman Hardy:

So there were two patients who were source patients. Then you mentioned 114 and 105 patients. The 105 patients had Hepatitis, but you were not able to link them directly, so what was the difference?

Brian Labus:

The nine cases we can easily say were related to the clinic, because we either had genetic testing, which was the case for seven of the nine, or they had acute disease, which means we can look at the six month window prior to the onset of their symptoms. They had no other risk factors in that period. For the 105 cases, these were people who did not have acute Hepatitis, so we could not look at a six-month time period; we had to look at their entire lives. Those people reported that they had none of the significant risk factors for Hepatitis C. None of them had prior lab testing that showed they were positive, and now they were confirmed to be positive for the disease. What we were left with is the Endoscopy Center of Southern Nevada or the Desert Shadow Endoscopy Center as the major risk factor for their infection with Hepatitis C. It is not as strong a link, but it is the major risk factor we identified for the infection of those patients.

Assemblyman Hardy:

And that was over a four-year period that you identified those 105 patients in addition to the 9 others.

Brian Labus:

It was a four-year period for the Endoscopy Center of Southern Nevada. The Desert Shadow Endoscopy Center was open only for two years.

Assemblyman Hardy:

Were any of the 105 patients identified from the Desert Shadow Endoscopy Center?

Brian Labus:

Yes, we had several from the Desert Shadow Endoscopy Center. The vast majority, however, were from the Endoscopy Center of Southern Nevada. We had a handful of the linked cases that were not strongly-linked, and we had one acute case that I mentioned where we were unable to do the genetic testing.

Assemblywoman Pierce:

Is there any possibility sometime in the future of being able to identify where the 105 cases were infected?

Brian Labus:

One of the major challenges is to actually do that identification. We need to do two things. First, we need to be able to identify the other patients on that date; we cannot even figure out who was in the clinic on that same date. We need to identify those patients. Then, secondly, we need to get the blood specimens because as time goes on this virus mutates rather rapidly. So, the more time that has passed from when patients were infected until our testing, the more likely it is that they are not going to have a very good match. We can show some percentage of matches, but as time goes on, it is a weaker and weaker match which does not produce that same kind of link as we had for the most recent cases.

Chairwoman Smith:

Talk to us about the domino effect in the community; the need for testing, the cost for that number of people to get tested, and how that is handled. And also address the impact of having those Endoscopy Centers closed.

Lawrence Sands:

I will do the best I can. Some of that information is really more anecdotal. Regarding the laboratory, it must be noted that we were not part of the main investigation on those two days the testing was done through laboratories like LabCorp and Quest Diagnostics. The approach that was taken, because of the sheer number of people being notified, was that we referred patients to their physicians to get the tests done, and also to be sure that they had a primary care physician who was familiar with their history and could guide them. The testing we recommended was for the purpose of screening so that we could quickly identify those patients who had an indication of being infected.

Much of the cost for testing was paid for by insurance. I talked with a number of the insurance companies throughout the outbreak. Many of them were doing follow-up with patients whom they knew, or for whom they already had claims established, or directing them to laboratory resources. For others, the laboratories were really very good in terms of testing at a low cost or no cost in some cases. LabCorp had an arrangement where someone who was unable to pay could ask for forgiveness of the fee. There was a big demand on the community, but everyone really pitched in. The actual cost of all the testing would really be difficult to estimate. We do not know how many of the lab tests had been done as a result of our notification. Many people were being tested for other routine reasons. Other people were being tested for reasons that had nothing to do with the clinic, but felt for some reason that they were at risk.

As far as the loss of the gastroenterologists in the community, it certainly did put a major crimp in the system. Many patients who were in the process of being diagnosed or managing a chronic gastrointestinal condition were left to find another provider, either to finish their work or to start anew, as well as provide the continuity of care that they needed for their chronic condition. Even before this outbreak, we had a very low number of gastroenterologists for our population in Las Vegas. The outbreak took out essentially 60 percent of those physicians, so that put a great demand on the ones remaining. Efforts have been made to recruit more gastroenterologists through University Medical Center and other places, and to connect people with the care that they need.

Assemblyman Stewart:

I assume there was a big drop-off in procedures requested and performed after this outbreak due to the lack of qualified doctors and because of patients' fears. Is there any indication that the confidence level has increased?

Lawrence Sands:

We do not have any specific information or any way to track that. Anecdotally, we do know that fear, and anger, in many cases, kept many people from seeking care. At SNHD, in our immunization clinic, we did see a drop-off in the days immediately following the announcement. One reason was because we are located directly across the street from the clinic where the outbreak occurred and our names sounded similar. Also, people who did come in asked if we were reusing needles; they wanted to see the packaging, and so forth. We worked with our staff to recognize those fears and concerns, and to change our practices so they could see us remove a syringe and needle from a fresh package each time. We demonstrated with the retractable needles that we use that it would be impossible for us to reuse the needle even if we wanted to. It took quite awhile to work through those issues with the community, and so

far, speaking for the Health District, our clinic attendance has returned to pre-outbreak levels.

Assemblywoman Pierce:

I remember reading that these clinics were trying to set a "land speed" record on colonoscopies; procedures that were supposed to take 15 minutes were reduced to 3 minutes. Have there been any incidents of people discovering that cancers had not been detected, then were later found?

Lawrence Sands:

I do not have any information to substantiate that. It is not something that we would collect.

Assemblyman Hardy:

In the spirit of disclosure, although I am not sure that I need to disclose this, I am a physician-member of the Southern Nevada Health District, when I am not here. I do not have any affiliation with any accreditation agency.

Chairwoman Smith:

Are there any other questions? [None.] Will you both be available in Las Vegas on Saturday? [They will.]

Darla Leibel-Burrow, Executive Director, Nevada Hepatitis C Task Force, Reno, Nevada:

[Ms. Leibel-Burrow had a PowerPoint presentation and a binder (Exhibit F).] We are here today to tell you about Hepatitis C. I am a Hepatitis C patient. I was infected as a result of a blood transfusion in 1984, and I am on a transplant list because treatment has been unsuccessful. We started this task force in order to raise awareness about this illness, to offer education to teach people how to protect themselves if they have the disease, and to share facts about how to prevent spreading it.

When the outbreak occurred in Las Vegas, we were there. We went to the first town hall meeting where people arrived in tears with letters from the Health Department about the outbreak centers; they did not know what to do. I was there to show them that I have lived with this for over 20 years, and I am still here. Many others like me were also there.

Somewhere the system failed us because the infection was first reported in 2004 by owners of the clinics in existence at that time. Nothing happened, and when those same people opened a new clinic, the same improper procedures went with them. I question how that was allowed to happen. The CDC and Southern Nevada Health District published information about acute Hepatitis.

Acute Hepatitis is contracted from chronic Hepatitis, which is what we all have or end up with. Acute patients become chronic, so we need to focus on the chronic patients, also, to stop the spread in the state.

I have put together, in this binder (Exhibit F), information that doctors across the country and I have gathered, including scientific data and ongoing studies. The number one cause in this country for liver transplantation is Hepatitis C. In our state alone, based on our population of 2.6 million according to the U.S. Census Report, the CDC determined 1.6 percent to be infected; that is over 40,000 people already infected with Hepatitis C. Add to that the 2 percent who have never been tested and do not know that they are infected, and that number is 50,000 plus. That is 90,000 people, in Nevada alone, potentially infected with Hepatitis C. In this room today are approximately 50 people; there are 7 of us known to have Hepatitis C—over 10 percent. We have done studies at the clinic on Wells Avenue in Reno. We tested 100 patients and found 30 patients were positive for Hepatitis C. That is a problem, and that is what we are here to explain: it is a bigger problem than people want to recognize. People want to sweep it under the rug and pretend it is no one's fault. It is not an IV-drug-user's disease, it is everybody's disease. Please listen to us.

Assemblywoman Spiegel:

Thank you for your excellent presentation. You mentioned that something about the Endoscopy Centers was known in 2004?

Darla Leibel-Burrow:

The press release in February, in Las Vegas, stated that the first known infection was in 2004.

Ken Morgan, Member, Nevada Hepatitis C Task Force, Reno, Nevada:

I have presented a handout [Hepatitis C Basics (Exhibit G)]. Hepatitis C is a blood-borne virus. Infection is transmitted by a chronic Hepatitis C-infected person; it enters the body through direct blood exposure. There is about an 80 percent chance to become chronic, and a 20 percent chance to clear the virus on your own. Those who do become chronically infected have a 20 percent chance of developing cirrhosis of the liver, and of that number, about 4 percent go on to develop either liver cancer or liver failure.

There are six major genotypes: 1A, 1B, 2A, 2B, 3, 4, 5 and 6. IA and 1B are the most common in the United States, representing approximately 80 percent of those infected. It is also the hardest to treat and eradicate. A person with 1A or 1B will be on treatment for at least a year, where a person with type 2 or type 3 might only need six months of treatment.

It is a ribonucleic acid (RNA) virus, rather than a deoxyribonucleic acid (DNA) virus, which attacks liver cells, and it multiplies and replicates. There is no vaccine for Hepatitis C. This disease can mutate millions of times a day, and that is why it is so difficult to come up with a vaccine. Over a period of from 10 to 40 years, 10 to 25 percent of those infected progress to serious liver damage, including fibrosis, cirrhosis, liver cancer, and liver failure.

The leading cause of transmission is sharing drug needles, IV drug use, but all drug paraphernalia can transmit Hepatitis C, even straws used to sniff methamphetamine or cocaine. Blood transfusions are another cause of transmission. I was diagnosed with Hepatitis C in 1999, which I contracted from a blood transfusion in 1982. About 1 to 3 percent contract the disease from sexual transmission which, when combined with other at-risk lifestyles like drug use, can increase to 15 to 20 percent. Needle sticks among health care workers is another cause, as is sharing household items (razors, toothbrushes, nail files or clippers) or anything that might have traces of blood that could be a potential cause of transmission for up to four days. Neonatal cases, children born to infected mothers, account for less than 5 percent. Tattooing has the potential to infect through the unsafe practice of an artist returning the ink left in the stylus back to the bottle following a tattooing. Body piercings are another potential source of transmission. There are also 10 percent of transmission routes that simply cannot be identified.

There is a difference between chronic and acute Hepatitis. An acute virus lasts six months or less, clearing on its own, but is infectious and communicable the entire time. A chronic virus is one that lasts more than six months and is always infectious. The symptoms for both acute and chronic are the same: flu-like symptoms, mild to severe fatigue, fever, night sweats, loss of appetite, nausea, vomiting, and jaundice. Other symptoms include indigestion, headache, muscle and joint pain, abdominal pain, depression, mood swings and brain fog or loss of cognitive function. When these symptoms are present, some people do not get tested because they believe they have the flu, or they are just getting older.

Before 1989, Hepatitis C was known as non-A or non-B Hepatitis, which is actually Hepatitis C. It was identified in 1989. The test for Hepatitis C was discovered in 1992. There are more than 250 million people infected worldwide, about 3 percent of the world population. More than 5 million Americans are Hepatitis C positive. The highest incidence occurs in 40- to 60-year old people. Those numbers do not include prison inmates (more than 41 percent of Nevada's inmates have the disease), the homeless, veterans, or children. Additionally, 10,000 to 20,000 people die from complications of Hepatitis C every year, and that number will triple in the next

ten years. One in every 500 children between the ages of 6 and 11 is chronically infected with Hepatitis C, according to the American Liver Foundation. In children between the ages of 12 and 19, the numbers are 1 in every 250 infected; nearly 1 million kids in our country, and most of them contracted the disease at birth. More troublesome statistics include 2.1 percent of Mexican-Americans, and 3.4 percent of the African-American population have Hepatitis C.

In a study done by University of California, Davis (UCD) in 1998, they found that by the year 2008, estimates suggested a 61 percent increase in cirrhosis from the numbers I have already stated, and a 279 percent increase in decompensation of the liver, which means the liver would go from working to not working. The study also estimated a 68 percent increase in liver cancer, a 528 percent increase in the need for liver transplantation, and 223 percent increase in liver-related deaths.

Chairwoman Smith:

Mr. Morgan, I am going to have to ask you to wrap up because we need to make sure that everyone gets a chance to testify, and we also have another presentation on the agenda.

Ken Morgan:

I would like to cover one last item. Hepatitis C virus cannot be spread by breast feeding, sneezing, hugging, coughing, food or water, sharing eating utensils or drinking glasses, or casual contact.

Chairwoman Smith:

And there is no vaccine?

Ken Morgan:

There is no vaccine for Hepatitis C.

Assemblyman Stewart:

You indicated you have had Hepatitis C for over 20 years, and that about 20 percent of those infected are cured. Do you know how they were cured, and is there a program that you are using?

Ken Morgan:

I have made a change in my lifestyle. I no longer drink alcohol, or eat fatty foods. I changed my diet, and every day I try to make my liver happy. No smoking or chewing tobacco, which are toxins. The liver filters toxins.

Assemblyman Stewart:

Have you noticed a decline in your health, or are you stable?

Ken Morgan:

No, I am actually getting worse.

Assemblyman Denis:

You mentioned that one cannot contract Hepatitis through food and water. Is that true of all types of Hepatitis?

Ken Morgan:

No.

Tom Ruble, Member, Nevada Hepatitis C Task Force, Reno, Nevada:

I have a PhD in counseling psychology. I am a social worker and have a master's in social work. I am currently a member of Northern Nevada Outreach Team which is involved in education and awareness, and does on-the-street testing of people for HIV. I am the Co-chair for People Living with HIV/AIDS for the Northern Nevada HIV/AIDS/STD Planning Council. I have been an AIDS activist for 25 years, since contracting HIV and Hepatitis C and being diagnosed in 1984.

I am here today as an advocate for Harm Reduction and Needle Exchange as a means of preventing transmission of these blood-borne pathogens. One of the things that we know about this epidemic is that, except in the case of rape and other such actions, HIV and Hepatitis C are almost 100 percent preventable The need for significant prevention education is with basic education. overwhelming. Statistically, about 94,000 people in Nevada could have Hepatitis C and/or HIV. The cost for the shots of interferon alone, not including doctor's visits and ancillary expenses, would be \$16.2 billion for just one injection a week for those patients over the course of approximately 18 months of treatment. Sometimes they have to go through the treatment twice. The shots of interferon cost \$1,200 each. It appears that there are for-profit companies that are willing to forego best practices for the bottom line, and that is very scary. We dodged a bullet in the Las Vegas outbreak earlier last year when only 100 or so people out of 60,000 contracted Hepatitis C.

If we learned anything from the beginning of the AIDS pandemic, it was that the government must deal effectively with prevention awareness. It would be shameful for us to behave in the way the administration did in the 1980s; denial at this stage of the game is costly, but it is also deadly. If we can educate our children and their parents about these risks and give them strategies for making better, healthier choices, we will prevent further spread of either or both of

these diseases. However, we need to get over our fear that by educating our children effectively, we encourage risky behavior. If we are going to truly arm our children with facts, we must be able to discuss routes of transmission which include sexual activity, sexual behavior, and drug-taking behavior.

At present there is no program for discussing sex or drugs in the public school system in Nevada. If we were willing to change or modify existing policies and laws restricting—not necessarily restricting because the empirical data says that we ought to, but because we moralize and judge behavior and make policy around that at times—what can be taught in the public school system, we could then provide the necessary strategies for them to negotiate and advocate for their own best interest. For example, effective condom use coupled with refusal and negotiation skills will empower our children and assist them to navigate the world. Fundamental education has been proven effective many The National Institutes of Health, in 1997, in an extensively times over. detailed paper, concluded that behavioral interventions will reduce the risk of HIV and AIDS, and there is a thin line between those diseases and Hepatitis C in terms of co-infection: 55 to 90 percent of those living with HIV/AIDS will or do have Hepatitis C. In my own case, in the 25 years I have been living with these diseases, I did not start treatment until 1998, and private insurance companies and the government have spent \$1.4 million to keep me alive. We now know we can prevent these diseases by telling people how to take care of themselves.

Legislative barriers to discourage effective programs aimed at youth must be eliminated. Although sexual abstinence is a desirable objective, programs must include instructions on safer sex behavior. The erosion of funding for drug abuse treatment programs must be halted, because research data clearly shows that those programs reduce the risk of behavior and often eliminate drug abuse itself.

Finally, the new research must focus on emerging risk groups such as young people. Last year in Nevada the number of cases of HIV among people between the ages of 13 and 24 doubled.

Chairwoman Smith:

I am going to have to do the same with you and ask you to wrap up, so we can make sure everyone has a chance to speak.

Tom Ruble:

I need to say, and a preponderance of evidence reveals, that harm reduction coupled with syringe exchange on the street level is effective in the drop of

sexually transmitted diseases (STDs), and it will reduce drug addiction and will keep people alive.

Chairwoman Smith:

It would be helpful to the Committee if you would leave a copy of your testimony. I will remind you that on Saturday we will be specifically addressing the legislation, so be prepared to address the bills.

Alex Lapasaran, Nurse Practitioner, Digestive Health Associates; Member, Nevada Hepatitis C Task Force, Reno, Nevada:

For the past six years I have been involved with individuals with chronic Hepatitis C, and my role ranges from screening and educating these patients in preventing transmission of the disease to treatment. Returning to Assemblyman Stewart's question about the 15 to 20 percent of patients who are cured, not everyone exposed to Hepatitis C will become chronically infected. We know that 15 to 20 percent do not become chronically infected. We believe that it is due to the robust immune system of those individuals at the onset of exposure. Some people will be fortunate enough not to become sick.

One thing not focused on today was the fact that chronic Hepatitis C is curable for 50 percent of patients. Mr. Morgan, who spoke earlier, alluded to the fact that there are six major genotypes of Hepatitis C. If one polled all those genotypes, 1 out of 2 patients would be cured with the standard of care that is currently available, namely, a combination of therapy with once-weekly interferon injections and daily ribavirin pills.

Shawna Jones, Nurse, Nevada Hepatitis C Task Force, Reno, Nevada:

I had Hepatitis C. I stand here before you as a ray of hope for all those who do contract the disease. I was told in 2003 that I had it, and we determined that I must have contracted it in 2001. By 2004, it was already killing me. I present the question to all of you: if you were told you had Hepatitis C but that you would live 20 years before it affected you, or before treatment was really needed, would you stand for that? I would not and did not.

The disease causes much co-morbidity in that 20-year span. Because the liver has 500 functions, it affects other parts of the body, and other illnesses develop such as kidney problems, pancreatic problems, and so on. All those problems become harder to treat when one goes through treatment. I had Hepatitis C 1A, the hardest to treat. I was told that treatment would not work, but to try anyway. Because I went through the treatment, I am cured. Early treatment and early testing are the things that may cure those affected. Waiting 20 years for transplantation will be costly to everyone and may not work.

Assemblyman Stewart:

What is the treatment?

Shawna Jones:

I went through one year of the maximum dose of interferon and ribavirin. That consisted of one shot per week and pills daily.

Sandy Curl, Director, Sierra Nevada Hepatitis C Support Group, Carson City, Nevada; Nevada Hepatitis C Task Force, Reno, Nevada:

I am also the facilitator of the Carson City Hepatitis C Support Group, and I have Hepatitis C. [Read from prepared testimony (Exhibit H).]

I want to tell you about some of the symptoms of Hepatitis C which I am aware of through my own experience and also through the experiences others have shared with me. Of course, everyone is different, and some people may not suffer with these symptoms. The symptoms of Hepatitis C may not appear until advanced liver disease is present; that is why early testing and treatment are so important. Symptoms include fatigue, general weakness, sleepiness, flu-like symptoms, fever, chills, muscle aches, joint pains, muscle wasting, arthritis, nausea, vomiting, weight loss and obesity, psychological disorders, depression, suicide, stigmata, irritability, isolation, insomnia, bruising, skin-itching—so severe that people end up with scars on legs and arms called pruritus—and so many others.

With all of these symptoms, medical costs can be astronomical and can go on for years. If people are given the chance for early testing and treatment, we can stop the spread and hopefully cure this disease before transplants are needed and more and more people die. I have been treated twice, and was a non-responder. Hopefully I can make it until a new drug comes out, and I can be treated again. Thank you for letting me speak today.

Darla Leibel-Burrows:

I just want to thank you again for allowing us to speak today. Hepatitis C was once called the silent killer. We are not silent anymore. We are out there talking and trying to get your help in introducing some kind of legislation. Perhaps a certification process to enhance the doctors' education on Hepatitis C will help them to better treat the disease. Currently it is being treated at gastroenterology centers, and they are overwhelmed. Because of what happened in Las Vegas, over 10,000 people, just in that area, tested positive for chronic Hepatitis C. We need help. We have families in Dayton and in Silver Springs where all family members are infected, and we do not know how that happened. People do not always admit how they contracted the disease.

Chairwoman Smith:

I want to clarify one thing for the record. Maybe Dr. Sands or Mr. Labus can help. The question came up about the 2004 issue. My understanding from your testimony was that infections from improper procedures went back to 2004 in your investigation, but it was not known at the time that someone had been exposed. I was concerned about the way Assemblywoman Spiegel asked the question about that.

Lawrence Sands:

When these cases were reported to the Health District, and the Health District went with investigators from the Bureau of Licensure and the CDC to the clinic, they looked at the practices and history of the clinic. What they learned was that the clinic had operated at that site and in that format since March 2004, so the records they had could only assess practices since then. There was nothing available prior to that date.

Chairwoman Smith:

I just wanted to clarify there was no knowledge back to 2004 of something happening. Ms. Spiegel, would you restate your question? I think I am not being clear.

Assemblywoman Spiegel:

I think you said it well. The question is whether there was any public knowledge that improper practices were being employed in 2004 or whether the knowledge of those practices that were occurring in 2004 was not known until 2008?

Brian Labus:

The problems we identified occurred in the past but were only recently identified. A good analogy would be a house fire where an investigation revealed faulty wiring and that the electrician had been installing faulty wiring for five years. We have now discovered a problem that had gone on for several years, and there was no indication early on that that was a problem. Had we known we would have stopped it back then, but we identified it recently and found that the problem had extended back some time in the past.

Chairwoman Smith:

We are going to move on to the next presentation on the agenda.

Mark A. Barry, M.D., Desert Orthopaedic Center, Las Vegas, Nevada:

[Read from prepared testimony (Exhibit I).] I represent a core group of approximately 20 specially-trained surgeons practicing in Nevada. Virtually all of us have private practices in which we see a high percentage of Medicaid

patients. We are advocates for tens of thousands of Nevada's most vulnerable children. These children, covered by Medicaid, are regrettably having difficulty getting access to medical care. Currently, approximately three-quarters of dedicated pediatric surgeons have been forced to close their doors to Medicaid patients; others have to ration access. Why is this? Unilateral reimbursement cuts made by the Medicaid Administration last fall have resulted in the most severe cut in the entire budget, by far, which is a base reimbursement reduction of 41.2 percent for care for patients under 21 years old. The situation was exacerbated by the introduction of the multiple procedures step-down scale, which can decrease reimbursement by double that amount in some more complex and extensive surgical cases. In addition, physicians have not seen a cost-of-living increase in Medicaid reimbursements for at least 18 years, despite the inflationary cost-of-living increase of approximately 63 percent over that time.

Not being able to afford to treat patients is very troubling to us. We feel a definite sense of social and moral imperative to try to use our talent, skills, and compassion to help our children in need. Over 95 percent of pediatric providers are in private practice in Nevada. We have no alternative sources of funding, like university and not-for-profit, hospital-salaried physicians may have. We are small business owners and operators; we have overhead expenses that average 30- to 60-plus percent. Each physician's income supports multiple employees and their families. These employees get medical insurance benefits, retirement plan matching contributions, sick pay, and yearly cost-of-living increases. With the current reimbursement cuts, nearly every office has been forced to lay off equally dedicated employees.

The majority of us live and work in Las Vegas. We are highly trained, conscientious, and hard working. Reasonable reimbursement rates 20 years ago helped attract us to Nevada. The future does not look good for attracting new doctors. New pediatric surgeons are in high demand. For example, currently there are approximately 25 jobs available for each graduating pediatric orthopedic surgeon. Reimbursement cuts have dropped us to 47th in the nation; Nevada does not look very attractive at all. We are the worst in the nation, by far, in Medicaid spending per enrollee, over 50 percent below the national average. Why is Medicaid being cut at all? Are our most vulnerable children not worth caring for? Who is going to look out for these kids if their families have difficulties and our government does not step up? The soundest economic and compassionate policy hinges on providing our children timely to quality medical care. Statistics show this, Medicaid Administration knows it.

A quote from the 2008-2009 Federal budget is, "Continued access to professional services is essential for the Medicaid program; providing adequate professional services improves health outcomes and reduces institutional costs." That quotation was under the title "Professional Fee Schedule Increase," perhaps an acknowledgement by the Medicaid Administration that physician reimbursement has dramatically fallen over the last 18-plus years in spite of inflation, without a single cost-of-living increase despite the fact that Cost-of-Living Allowance (COLA) is routinely extended to 93 percent of the rest of the Medicaid services in the budget, including Health Maintenance Organizations (HMOs), which do not pass it on to medical providers despite receiving an 85 percent payment increase since 2002. The fee schedule increase I mentioned was to be 24 percent. The state is trying to save \$3.78 million with these cuts. This is a miniscule 0.29 percent of the Medicaid budget, and less than 0.1 percent of the federal stimulus amount of \$450 million coming to Nevada Medicaid. This short-term saving will surely pale in comparison to costs involved in sending children out of state, not to mention the family's social, emotional, and economic hardships. Where do we send our kids? The state is finding out that surrounding states are no longer willing to accept our kids due to poor Medicaid reimbursement. Already several critically ill children have suffered unnecessarily due to delays in care and attempts to negotiate with out-of-state hospitals.

What does the future hold? It holds increased economic hardship, increased Medicaid enrollment, a potential three-fold increase in Nevada Checkup enrollment, et cetera. We, as physicians, can treat these children; we absolutely want to treat them. However, we have to stay in business to do so. Please allow us to do what we do best. Let us hire back laid-off employees, reverse the Medicaid reimbursement cuts, and insure that we do not end up in crisis in the future by allowing us basic cost-of-living adjustments in the years to come. We request that this be done immediately as a special legislative action, so access can be restored as soon as possible for Nevada's children.

Chairwoman Smith:

Thank you, Dr. Barry. Committee, I know that this is basically a fiscal issue, but I think it is also a larger issue when we are talking about the health care in our state, and we read about it so much in the press that I thought it was important for you to hear this information. I also want to mention that we had witnesses in Las Vegas who were there to testify, but the building has been evacuated due to a security issue, so our witnesses are not there. We think everything is fine now, but we do not have anyone in the audience. If anyone comes in later, we will call on them.

Assemblywoman Spiegel:

Dr. Barry, I do recognize what you are saying, that you have to stay in business. I was talking to a pediatric oncologist who told me that out of every month he works, the first 28 days are to pay his office overhead and the remainder of the month is what he winds up with for his salary and compensation. When you look at February, that is kind of scary, actually scary no matter what, but I am wondering whether his experience was representative or an anomaly.

Mark Barry:

The most significant thing is that people are seeing reimbursements decline and fixed overhead costs increase. So we are getting closer and closer to the end of the month before we are giving ourselves a paycheck. His example is extreme, and I would suspect his overhead is around 80 percent. The average is 30 to 60-plus percent, but as our reimbursements come down because we are not seeing these kids, our overhead will be in that neighborhood as well.

Madam Chair, I would like to introduce Edwin Suarez, a very good physical therapist, born and raised in Las Vegas. As an orthopedic surgeon, what therapists do is critical to the success of many of our surgeries, especially with children who have complex issues like cerebral palsy, spina bifida, and so on. I am concerned that with the cuts they are facing, my kids will not have access to the physical therapy care they need, so it affects us as well.

Edwin Suarez, Physical Therapist, CEO/President, Physical Therapy, LLC, Las Vegas, Nevada:

Thank you for extending this time for us to speak. I want to give a PowerPoint presentation about how physical therapy benefits our children and the State of Nevada. [Mr. Suarez provided a handout of his presentation (Exhibit J) and read from prepared testimony.]

Physical therapy is a profession devoted to the restoration, maintenance, and promotion of optimal physical function. It helps patients maintain health by preventing further deterioration and further illnesses. Physical therapy is practiced in hospitals, out-patient clinics, offices, in-patient rehabilitation facilities, skilled nursing facilities, extended care, sub-acute facilities, patient homes, education and research centers, as well as schools and hospices. Physical therapists are professionals who diagnose and movement-dysfunction, and enhance physical and functional status, in all age Physical therapists help patients maintain their health by preventing further deterioration and future illnesses.

Pediatric physical therapy is a highly specialized aspect, requiring one-on-one individualized care. The State of Nevada Medical Practice Act requires physical

therapists to practice with high standards. The Nevada Physical Therapy Association (NPTA) is concerned that as the Medicaid system is streamlined to become more cost effective, optional services such as physical therapy are being marginalized. [Mr. Suarez continued reading from his prepared testimony.] I also have some video testimony, however, due to lack of time, I will skip that.

How can our elected officials help? They can provide us with the financial means to reopen our doors to our pediatric population and recruit new practitioners for this under-served group. Currently, 40 percent of our total revenue comes from Nevada Medicaid. The reimbursement rate cuts have made it impossible for us to continue to treat pediatric patients. At the current reduced rate, we cannot afford to treat the pediatric population and meet our business overhead; it is impossible. We ask that you reverse the pediatric reimbursement rate cuts handed down on September 8, 2008, and restore access for the pediatric population, for all specialty services, physical therapy, pediatric surgical specialists, occupational speech therapists, and save our state money by avoiding the deleterious effects that this budget cut is having on our pediatric population.

Chairwoman Smith:

I am assuming that with your specialty and perhaps with the other therapies as well, it is not like a patient can just go out of state to have physical therapy three times a week. The children probably get it at home, or they just do not get it.

Edwin Suarez:

They do not get it. The children need therapy two or three times a week minimum for many of these diagnoses. It is either through our practice or the Children's Therapy Center; we are the only providers for pediatric physical therapy, as far as I know. There may be a few small providers, but we are the two largest. Children's Therapy Center has a 70-child waiting list. We stopped taking Medicaid on February 1, 2009. We have a 15-child waiting list.

Leann Sparks, Physical Therapist, Home Health Care; Vice President, Nevada Physical Therapy Associates, Henderson, Nevada:

I am a practicing physical therapist in a home health setting, and I am also Vice President of Nevada Physical Therapy Associates. Edwin Suarez and our other colleagues in the out-patient setting do provide the pediatric physical therapy. As a home health physical therapist, we have not accepted any new Medicaid patients in the last four years. In response to the question "Do they go home and have it at home?" there are very few clinics in the Las Vegas area that I can speak for that do home therapy. We are one of those, and we do not

accept any Medicaid patients. If patients do not have the ability to transfer themselves via their parents to an out-patient clinic, I can tell you they are not receiving the care at home.

Chairwoman Smith:

When did you stop taking Medicaid?

Leann Sparks:

We stopped taking Medicaid in 2004.

Chairwoman Smith:

Why was that? I thought the testimony was that the rates were still decent then.

Leann Sparks:

The rates were decent then, however, there were obstacles in submitting insurance claims to Medicaid and the approval process required. And though we would obtain approval for home health therapy and continue to see the patient, we would then not be reimbursed at all. Our claims were denied. The overhead expenses in treating those patients and recouping those costs did not make business feasible.

Chairwoman Smith:

Do we think that has gotten better?

Leann Sparks:

It has not gotten better.

Assemblywoman Mastroluca:

How many patients do you turn away because they come to you with Medicaid, versus how many patients you actually serve now?

Edwin Suarez:

We did not have a waiting list prior to these cuts, so we were able to treat these children even though the previous rates were still low. We never turned anyone away. We are turning all pediatric patients away now, Medicare and private insurance included. We cannot see any children at this point; so much of our population is Medicaid, as I mentioned before. We do see an adult patient caseload, and we are going to have to start focusing on that because it is a matter of business survival. We can no longer do it with pediatrics.

Robyn Kaiser, Occupational Therapist, Director, "Sense"ational Kids, Las Vegas, Nevada:

I am a pediatric occupational therapist. I also have a private practice in Las Vegas, and 95 percent of my caseload is Medicaid. I have 12 contract employees. I am a very unique service, one of less than five in the valley. As far as turning away patients, I also have a waiting list; because there are so few clinics that specialize in pediatric services, there is a waiting list everywhere to get quality pediatric services. A pediatric client cannot be sent to an adult clinic. I have over 80 clients on my small business caseload and the number grows every week.

Chairwoman Smith:

Can you please tell us what you do?

Robyn Kaiser:

I am a member of the Nevada Occupational Therapy Association. [Presented a position statement from Nevada Occupational Therapy Association (Exhibit K). The pediatric occupational therapists and occupational therapy assistants are nationally board-certified and state-licensed. From a pediatric standpoint, we are experienced in typical development as well as atypical development, and we work on skills such as eating, toileting, bathing, grooming, dressing, playing and interacting successfully with family members, being able to provide children with the skills they need to lead productive and normal lives, and to grow and develop. I think that we have not really turned away clients, because we are extremely dedicated and we are still weighing our long-term abilities. Are we going to be able to stay in business, or is it time to do something else? There was a 33 percent rate cut to therapy overnight, and with overhead, that is a lot from a small business perspective. I am faced with the personal decision of not doing what I do anymore, and going to work behind a desk, or at a school district somewhere, because I can no longer make ends meet. The problem has not really surfaced yet, but it will, if the cuts are not reversed. If we took only a 5 percent cut like others did, there might not be such a fight, but we took a 33 percent cut. We understand what is going on in the country right now, but it is going to hurt the children in the long run and it will hurt the state as well because we are all going to pay for it in the end.

Edwin Suarez:

I was recruited by the State of Nevada to serve this population. I was a Western Interstate Commission for Higher Education Scholarship recipient. I was studying in California, and I came back home after graduating in 2002 and made a commitment to see these children. I fell in love with the profession, and we make a tremendous difference. I believe in what I do. Robyn and Leann believe in what they do, and we all want to continue to do that. I want to do what the

state paid me to do, what it put me through school for, and that is to see these children, make them better, keep them off equipment and orthotics, and make them as independent as possible so they can be positive contributors to our society. That will not happen at these reduced rates. We have looked everywhere to reduce costs; we just cannot do it.

Robyn Kaiser:

A large concern of many of my clients is the accessibility of specialty physicians. Without the accessibility of the orthopedic surgeons, surgeons in general, or gastroenterologists, it makes my job impossible, and I cannot do my part in rehabilitating some of these children. I think that many, many children are unable to get the services. There is nowhere for them to go, and many families cannot afford to go out of state, even if their insurance or Medicaid will provide the treatment. Because the parents cannot afford to leave work or need to take care of other members of their family it cannot happen, and once again the children will not get the treatment they need because it cannot be provided in-state. In the long run it costs the state more money.

Chairwoman Smith:

We have Committee members who need to get to another meeting. Dr. Barry, do you want to wrap up?

Mark Barry:

I had several doctors in the Grant Sawyer Building who are unable to testify. One of the doctors, a pediatric surgeon, sent me his testimony on my phone; it is about four minutes long.

Chairwoman Smith:

You will lose this Committee, because in two minutes we have another Committee starting. What I ask is that you forward that testimony to me, and we will copy it and get it to our Committee members. We are sorry that they were not able to testify because of the security issue in southern Nevada.

Edwin Suarez:

Parents are the biggest advocates for their children and for the benefits of physical therapy, and I will email these testimonials to you.

Chairwoman Smith:

We would be happy to receive that. This morning in the Committee, Speaker Buckley made a general statement about the situation we are in, and how we are all trying very hard to get our arms and our brains around what is going on in our state, and what we can do about it. You are all very beleaguered, I can tell. It is frustrating, I am sure you are tired, and we feel much the same way.

We hear these stories every day in the money committees and in the policy committees. It is very difficult to be at the bottom of every list you do not want to be at the bottom of, and the top of every list you do not want to be at the top of. So, we appreciate your situation, and we appreciate the time and effort you have made. I often say that teachers and health professionals just want to be able to do their jobs; they do not want to be out advocating; they just want to do their jobs and take care of the kids and patients. We understand that and we appreciate what you are faced with, and that you are trying to make it better for yourselves, for your employees, and for your patients. I assure you and I believe with all my heart that the people in this building are doing everything in their power to try to make it better.

Thank you all for coming. I imagine we will see you again before we are out of this Legislative Session. We welcome your information, and anything you want to send to me or my staff, we will make sure the Committee has it.

Is there any other public testimony to come before this Committee? [None.] If not, we will reconvene on Saturday morning at 8 a.m., in Las Vegas.

Meeting adjourned [at 3:47 p.m.].

	RESPECTFULLY SUBMITTED:	
	Darlene Rubin Committee Secretary	
APPROVED BY:		
Assemblywoman Debbie Smith, Chair		
DATE:		

EXHIBITS

Committee Name: Committee on Health and Human Services

Date: February 18, 2009 Time of Meeting: 1:30 p.m.

Bill	Exhibit	Witness / Agency	Description
	A		Agenda
	В		Attendance Roster
	С	Richard Whitley, Administrator, Health Division, Department of Health and Human Services	Infection Control Practices in Nevada
	D	Lawrence Sands, D.O., M.P.H., Chief Health Officer, Southern Nevada Health District, Las Vegas, Nevada	Prepared testimony, including Investigative Timeline and Overview, and Graph of Unsafe Injection Practices and Disease Transmission, and UNLV Nevada Public Health Survey
	E	Brian Labus, M.P.H., Senior Epidemiologist, South Nevada Health District, Las Vegas, Nevada	Prepared testimony
	F	Darla Leibel-Burrow, Executive Director, Nevada Hepatitis C Task Force, Reno, Nevada	Binder of Hepatitis C- related information
	G	Ken Morgan, Nevada Hepatitis C Task Force, Reno, Nevada	Hepatitis C Basics printed matter
	Н	Sandy Curl, Director, Sierra Nevada Hepatitis C Support Group, Carson City, Nevada	Prepared testimony
	I	Mark A. Barry, M.D., Desert Orthopaedic Center, Las Vegas, Nevada	Nevada Medicaid Reimbursement Cuts
	J	Edwin Suarez, Physical Therapist, Physical Therapy, LLC, Las Vegas, Nevada	How Physical Therapy Benefits Our Children and the State of Nevada
	K	Robyn M. Kaiser, Occupational Therapist, "Sense"ational Kids, Las Vegas, Nevada	Statement of the Nevada Occupational Therapy Association