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

Seventy-Fifth Session
March 30, 2009

The Committee on Health and Human Services was called to order by Chair Debbie Smith at 1:38 p.m. on Monday, March 30, 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
Assemblyman Ty Cobb
Assemblyman Mo Denis
Assemblyman John Hambrick
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:

Assemblywoman Peggy Pierce, Vice Chair (excused)

GUEST LEGISLATORS PRESENT:

None

STAFF MEMBERS PRESENT:

Amber Joiner, Committee Policy Analyst
Chris Kanowitz, Committee Secretary
Olivia Lloyd, Committee Assistant

OTHERS PRESENT:

Alicia Hansen, Chief Biostatistician, Bureau of Health Statistics, Planning, and Emergency Response, Health Division, Department of Health and Human Services
Christine Wood, Section Manager, Chronic and Communicable Disease Programs, Health Division, Department of Health and Human Services
Sheila Baez, Steering Committee Chair, Nevada Cancer Council, Reno, Nevada
Tom McCoy, State Director, Governmental Relations, American Cancer Society, Reno, Nevada
Stacey A. Gross, Community Programs Manager, Southern Nevada Affiliate of the Susan G. Komen for the Cure, Las Vegas, Nevada
Lewis Musgrove, Chair, Governor's Task Force on Prostate Cancer, Health Division, Department of Health and Human Services
Mary Guinan, State Health Officer, Health Division, Department of Health and Human Services
Julie Tholl DeJan, Executive Director, Angel Kiss Foundation, Reno, Nevada
Jennifer Bradley, Executive Director, Candlelighters Childhood Cancer Foundation of Nevada, Las Vegas, Nevada
Alexa Walker, Private Citizen, Las Vegas, Nevada
Mark Fiorentino, representing Nevada Partnership for Homeless Youth, Las Vegas, Nevada
Callyce Carroll, representing Nevada Partnership for Homeless Youth, Las Vegas, Nevada
Charles Duarte, Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services
Elisa Maser, representing Nevada Advocates for Planned Parenthood Affiliates, Reno, Nevada
Joanee Quirk, Program Administrator, Prescription Controlled Substance Abuse Prevention Task Force, Nevada State Board of Pharmacy
Carolyn Cramer, General Counsel, Nevada State Board of Pharmacy
Rocky Finseth, representing PhRMA, Las Vegas, Nevada
Clemmet Cypra, Policy Counsel, PhRMA, Washington D.C.

Chairwoman Smith:
[The roll was taken. A quorum was present.]

Assemblyman Stewart:
I would like to congratulate the Chairwoman on being selected to the Hall of Fame of the Education Foundation.

Chairwoman Smith:
Thank you. It was an honor for me. I served at Governor Guinn's pleasure as the Chairman of the Academic Standards Council for many years.

We have a number of presentations regarding cancer information in our state. We also have some bills to hear. We will go ahead first with the presentations.

Alicia Hansen, Chief Biostatistician, Bureau of Health Statistics, Planning, and Emergency Response, Health Division, Department of Health and Human Services:
My presentation and information from several of my fellow presenters can be found in a bound document (Exhibit C). It is also available on line at <www.health.nv.gov>. I am here today to talk about the Nevada Central Cancer Registry. A cancer registry collects data regarding cancer diagnoses, treatment, and mortality. It is population-based, aiming to collect information on every cancer diagnosis of Nevadans.

To allow time for treatment information to be available, the data collection is retrospective, typically with a one- to two-year delay in collection and reporting. Registries do not track incidents as diagnoses occur. Thus, they do not contain real-time data. They cannot be used to identify emerging cancer clusters.

The data in the Registry is used to calculate rates of cancer occurring in Nevada. Further, the identified data is reported to the Center for Disease Control and Prevention (CDC), the National Program for Cancer Registries (NPCR), and the North American Association of Central Cancer Registries (NAACCR) to allow for national reporting. More information is available on the Cancer Registry website.

Data is collected in several ways. State cancer registrars visit facilities and abstract cases. Other facilities have their own registrars that abstract cases and submit information to the registry. We also receive reports from pathology labs. Further, we have agreements with eleven states, including several surrounding states, to receive information on Nevada residents who are diagnosed with or treated for cancer in those states. Information from all of these sources is consolidated and final comprehensive case reports are used for analysis and reported to NPCR and NAACCR.

Currently, the Registry receives approximately 17,000 case reports annually and reports nearly 12,000 cases after the consolidation of the data. The two national organizations the Registry reports data to, NPCR and NAACCR, set national standards for data quality and completeness. The Cancer Registry has received Gold Standard Certification, the highest rating from NAACCR for the past six years. We anticipate that we will receive Gold Standard Certification for a seventh year. We are often rated poorly for our public health indicators here in Nevada, however, our Cancer Registry has some of the best data in the country.

The Cancer Registry links with many other programs and entities for case finding, acquiring supporting information, and improving surveillance and data quality. These include the State Office of Vital Records, hospital discharge data collected under contract by the Division of Health Care Financing and Policy, the Women's Health Connection, Breast and Cervical Cancer Early Detection Program, and Indian Health Services.

The Cancer Registry data has great value for Nevada. It can be used to identify areas where Nevada differs from the rest of the country, including identifying burden of disease and disparities. This allows prevention programs to target interventions as well as create information for policy development and evaluation of program outcomes. Due to the consistently high quality of Nevada's data, information is included in nationally published statistics and is extremely valuable for research.

There are many ways to access Nevada cancer statistics. One excellent resource is the most current version of the "Report on Cancer in Nevada: 2000-2004." This document is available on the Health Division website. Statistics are also available online from the CDC via the United States Cancer Statistics website, from NAACCR via Cancer in North America, plus online and publications websites. Links to all of these resources appear in the handout (Exhibit C) on page 12.

We have many plans to enhance the Registry in the future. These include linkages with the National and Social Security Death Indices, web-enabled reporting for facilities, and geocoding of the data. We are also exploring options for building infrastructure in information technology, data analysis, and data quality control.

I would like to share two examples which show the value of the Cancer Registry data. From 2000 to 2005 the incidence of invasive lung and bronchus cancer in Nevada declined from the 3rd-highest in the country to the 24th-highest. That is a significant decrease in cases. Over the past decades smoking rates in Nevada have dropped from being the 2nd-highest in the nation to being 16th. This indicates that something is going right.

If we break those statistics down further, we find something unusual. As I mentioned, in 2005, Nevada ranked 24th overall for lung cancer incidence. If we break that down by gender, we find that Nevada males have the 31st-highest rate, and females have the 9th-highest rate. This indicates a need to target prevention efforts towards women. Interestingly, while smoking prevalence among women has declined over the last ten years, lung cancer incidents remain high compared to other states.

We can also compare Nevada's statistics to national results. The graph on page 18 in your handout shows a comparison between Nevada and national rates for several of the most common cancers. I would like to focus on colon cancer rates. From 2001 through 2005 Nevada had the 37th-highest rate of colon and rectum cancer in the country, slightly less than the national rate. A survey in 2004 revealed the colon cancer screening rates in Nevada were also slightly lower than the national rate. Screening rates are lower than national but so are cancer rates. Which leaves us with the question of why? This reveals an opportunity that we have for further investigation using the data in the Registry.

There are many future opportunities for utilizing the Cancer Registry data. This is just one example. There is a great need for further dedicated data analysis to provide more needed information and to analyze identified issues more in-depth. Integrating cancer data with other health-related data in a data warehouse would allow for additional focused analysis revealing where public health efforts should be directed. Existing programs could utilize this information to target interventions and improve health outcomes for Nevadans. We are exploring ways to make these possibilities into realities.

Assemblyman Hardy:
If our screening rates are down and our cancer rates are down, it seems to me that if we do not screen, we will not find. Am I missing something?

Alicia Hansen:
I think that would be a good conclusion based on that information.

Chairwoman Smith:
I have a couple of questions. I am assuming that our system has changed since the onset of the Fallon leukemia cluster, because I remember that part of our issue was that we were not able to see all of that data, so we stumbled onto the original findings. Is that the case?

Alicia Hansen:
The data in the Registry, unfortunately, does have a certain time delay on it because they have to go back and abstract the cases once diagnosis and treatment has been done. The quality of our data is getting better all of the time as far as what we are collecting; however, there is no real-time data as cases are diagnosed in Nevada.

Chairwoman Smith:
Why are we still at 2005 numbers? Also, can some of the health technology money that we will be receiving from the stimulus dollars help improve this process to bring us current information? It seems crazy to be three years behind in today's world.

Alicia Hansen:
We actually just finished abstracting the 2006 data and submitted it, so that data should be available shortly for statistics. We are currently collecting the 2007 data.

Chairwoman Smith:
Is there a plan to speed that up? It still seems amazing to me that we are in 2009 and we are still collecting 2007 data.

Alicia Hansen:
At this time, I am not aware of any plans at the national level to change that reporting schedule. The two national organizations that we report to have 12- and 24-month completeness time frames. At 12 months following diagnosis, we have a fairly high completion rate. I think we are aiming for 90 percent case ascertainment at that point.

Assemblyman Stewart:
Is there any indication as to why the smoking rates and the cancer rates dropped? Are other states doing worse or are we really doing better?

Alicia Hansen:
The CDC recently published in their mortality and morbidity weekly report an overview of smoking rates in the country and they looked at the last ten years using behavioral risk factors and surveillance system data. We actually had the

steepest decline in smoking rates of any state in the country during the ten years from 1998 to 2007. The efforts of public health and all of the people involved in trying to encourage people to stop smoking appears to be having a beneficial impact on both smoking rates and hopefully, by extension, lung cancer rates.

Chairwoman Smith:
Are there any questions from the Committee? I see none.

Christine Wood, Section Manager, Chronic and Communicable Disease Programs, Health Division, Department of Health and Human Services:
[Spoke from written testimony (Exhibit D).]

Chairwoman Smith:
Are there any questions from the Committee? I see none.

Sheila Baez, Steering Committee Chair, Nevada Cancer Council, Reno, Nevada:
I would like to speak a little about the Nevada Cancer Council, which is a collaboration of stakeholders from throughout the state, and describe our efforts to implement the cancer plan for the State of Nevada. [Distributed an outline and written testimony (Exhibit E).] The plan can be found in the booklet provided by Ms. Hansen (Exhibit C). It was published in 2006 with a forward from Governor Guinn that was written in 2005. I have written a description of the Council activities, which is on page 69 of the booklet from Ms. Hansen.

The network is dedicated to the mission of conquering cancer. The national partners in the comprehensive cancer network are made up of private, public, and nonprofits across the cancer continuum. The American Cancer Society, the American Commission on Cancer, the Association of State and Tribal Territories, the CDC, the Lance Armstrong Foundation, and the National Cancer Institute, are all national members of this network that is providing our Council in Nevada with a framework to move forward. One member of that coalition, called C-Change, is dedicated to helping state coalitions make a difference and implement their plan. They put great literature out such as the booklet *Increasing Access to Cancer Care* and the *Action Guide to Comprehensive Cancer Control Coalitions*. This national effort helps those of us in smaller organizations just getting started in states, especially western states, which are slightly isolated from Washington D.C. and the movements of the larger states. Other states in the country have had their coalitions in place for ten-plus years. I was elected one year ago as steering committee chair when it basically was started.

We are structured with a steering committee, plan implementation committees, small task forces, and operational committees. I will tell you a little bit about the activities of these different committees. Our membership is listed on page 74 in your document (Exhibit C). Each organization has a number of people who might be active on different committees. I do not have the total number of members in the Council but we are constantly growing.

This Council is made up of providers like hospitals, nonprofits like the American Cancer Society, many of the other foundations, payors–the insurance companies—governmental policy makers, public health officials, academicians, and cancer survivors.

Activities of our steering committee in 2008 included the first annual cancer control summit. We were very proud to offer this summit on December 6 in Reno, Nevada. It was at the Peppermill Resort Casino. Having an annual summit falls under some of the plan guidelines, especially Goal 6 which is to improve collaboration and coordination among cancer control efforts throughout the state. We wanted to increase awareness of the national cancer control effort, to provide information on the state of our state in regard to comprehensive cancer control, to mobilize our Nevada stakeholders to move the state forward, and ultimately to improve the quality of life for Nevadans affected by cancer. Approximately 130 people attended the summit, including Chairwoman Smith. The faculty at the summit included national and local cancer leaders, and Hala Moddelmog, who is the President and Chief Executive Officer of the Susan G. Komen for the Cure Foundation. We also had presentations from public health and state government officials.

This summit was underwritten by several organizations within the state including Renown Institute for Cancer, the Carson-Tahoe Cancer Center, Candlelighters, Childhood Cancer Foundation, our CDC grant, and several of the pharmaceutical companies. We intend to offer the second annual summit in November to December of this year. It will be held in Las Vegas, and we are very grateful that St. Rose Dominican Hospital has offered the use of its conference facilities free of charge to the Council, which will make a tremendous impact on our ability to recruit speakers at the national level. We hope that legislative representation is there because we need to work together as a community and the input from the Legislature, and its participation, will really help us move the cancer process forward in the state.

One of the recipients of the Extra Mile Award (EMA) was Bill's Casino in Lake Tahoe which is a 100 percent smoke-free casino. We will move this award forward each year, and we would like to have as recipients next year a legislative person, a business person, a nonprofit entity, and a cancer survivor, and give several of these awards each year to those people in Nevada.

There was mention earlier about the rates of smoking in the state going down. One thing I want to comment on was that, although smoking rates are down in the state, they are up for young women. That is a particular area that our committee would like to look into, impacting education for young women in this state who are still smoking at alarming rates.

This weekend, the mayor of Sparks was featured on Channel 4 news. He had a colonoscopy last week and the mayor of Reno was there to cheer him on. This was in response to Dr. John Gray speaking with them both about the importance of colon cancer screening. In addition, Dr. Gray has organized a primary care doctor education program and we are working with a doctoral student in southern Nevada to put together a tool kit for primary care providers. The reason this is so important for colon cancer is that we know, and studies have shown, that individuals who are told to get a colonoscopy by their physician usually get it. We are trying to educate our public and our primary care providers.

The goals for 2010 focus mainly on expanding our membership. The state is facing crises, as many of you know, and this is reflected in providers and positions being eliminated in many organizations throughout the state. My position at Renown Institute for Cancer has recently been eliminated. Angela Berg, our representative from Candlelighters, had her job eliminated a week or so ago. Many organizations in the state today are focusing on survival. Therefore, they are looking more inward and have less ability to support statewide initiatives. This is a real crisis for our Council in terms of membership, and I think it is a period of time that we just have to work through.

As an organization, we are working towards becoming a 501(c)(3) and getting nonprofit status so that we can apply for grants in order to move some of our initiatives forward.

Chairwoman Smith:
Are there any questions from the Committee? I see none.

Tom McCoy, State Director, Governmental Relations, American Cancer Society, Reno, Nevada:
You will see from my prepared materials (Exhibit F) some information about the American Cancer Society (ACS) and our presence in Nevada. I am not going to take time to give you that information during this presentation.

The American Cancer Society has been a key developer of comprehensive cancer plans in all of the states.

My position is that any disease that can kill is ugly and Nevada's cancer numbers are ugly. We develop cancer estimates from our work with the CDC, so our numbers, perhaps, are more up-to-date. In 2008, we had the same number that we heard earlier, about 11,000 new cases of cancer in Nevada and almost 4,500 deaths from cancer. Nevada's most prevalent cancer is skin cancer and that is why we have actively supported legislation from Assemblywoman Koivisto and Senator Copening that addresses skin cancer issues in Nevada.

In subsequent order of prevalence there is lung cancer, which accounts for about one-third of our cancer deaths in the state. That is one of the reasons the American Cancer Society was involved in initiating the efforts to enact the Nevada Clean Indoor Air Act.

This afternoon we have discussed the need for increased funding for tobacco control and prevention programs from Nevada's share of the tobacco settlement payments. Direct and second-hand smoke kills and sickens Nevadans and it costs us more than the state takes in from tobacco tax revenue.

The next in occurrence is prostate cancer, followed by breast cancer, and then colorectal cancers. Preventive efforts and early detection can reduce the ugly numbers associated with these cancers.

From the ugly, let us turn to the bad. The bad is that cancer exists at all in the State of Nevada and that it will impact, directly or indirectly, nearly everyone on the Committee at some point in your life. And, for some, it already has. Nevada has an access-to-cancer-care-and-treatment crisis throughout the state. It is especially true in the rural areas where cancer patients have to travel hundreds of miles for diagnoses, surgery, and treatment. The cancer community is supporting a pending bill that will provide some help in requiring parity in how the insurance industry in our state treats payment for oral chemotherapy. That usually can be taken at home and can make a big difference for our rural Nevadans.

Unfortunately, we lack cancer specialists, especially pediatric specialists, in Nevada, which forces our children to leave the state to be treated. That is an impact not only on the child, but also the family. You will hear more on that later. There were 841,000 Nevadans under 65 who were uninsured at some point last year. Some in Clark County that sought cancer help at a county hospital were turned away. We are not using the media effectively to get the message out about cancer in Nevada and what resources are available.

The good part of this trilogy is as follows: many of us here and those associated with the Nevada Cancer Council have full-time jobs in a medical setting with a nonprofit, health-oriented association such as mine, the American Cancer Society. Most of us go above and beyond our job duties to fight back against cancer. We do this because we are Nevadans who care about cancer and we care about our neighbors. We do not want you to experience it, ever. If you do, we want you to know that we will do everything we can to help. Our collective goal is to control cancer in Nevada and, as you have heard, we have a comprehensive plan to do so.

I have some really good news for this Legislature that has to struggle with competing demands for appropriations and a decreasing source of revenue—we do our work at no cost to the State of Nevada. You have heard the story of Dr. John Gray. I think it is important to focus on him for just a second. This is a gentleman who took it upon himself and his checkbook to make a difference in colon cancer in Clark County and in the state overall. He is heading up the colon cancer task force. I became involved in a situation concerning a lady in Las Vegas who had a history of cancer and was told by her doctor to go and see an oncologist. She was turned away from the University Medical Center (UMC) when they closed their oncology department. She had a Clark County short-term medical card, but she could not get an appointment within the time period before the card expired. Bob Fischer of Nevada Broadcasters told me about it, and I told him I was certain we could get some help in the north. Bob volunteered to pay her travel costs to Reno. I contacted professional friends on the Cancer Council who helped set up an appointment within days, and she was checked out and received good news.

It is all about the cancer community in Nevada coming together. Another example is the Carson City Colon Cancer Summit that ACS is providing some jump-start funding for. It is a pilot project of a community coming together from all corners to talk and plan a community response to that specific cancer. This is a model for other communities in our state.

A good example of Nevadans coming together, and something that I am very proud of because I am associated with the American Cancer Society, is the thousands of Nevadans who take to the tracks throughout the state in spring and summer to raise money and awareness by participating in the ACS Relay for Life.

The gentleman who started Relay for Life, Dr. Gordon Klatt, 25 years ago was a physician who just wanted to do something to provide a little spark to his patients. That effort, by one man, has raised about $3.5 billion for cancer research.

When it comes to cancer, Nevadans come together in a wonderful way. Those of us who have had cancer could sing along with Sister Sledge, "We are family," because we are and we show it in many ways. I invite you to come out to a Relay for Life event, see it first-hand, and follow the work of this Council. We are cancer in Nevada. If all of us come together to fight this ugly killer and overcome some of the bad response, the good will win out for everyone in Nevada.

Chairwoman Smith:
Are there any questions from the Committee? I see none.

Stacey A. Gross, Community Programs Manager, Southern Nevada Affiliate of the Susan G. Komen for the Cure, Las Vegas, Nevada:
Our organization is dedicated to saving lives and ending breast cancer forever. My comments will be more specific to breast cancer. [Distributed outline of testimony, (Exhibit G).] In Nevada we work through two affiliates, a northern and a southern affiliate, and primarily raise funds to fulfill our promise. What you might not know is that 75 percent of the funds that we raise in our local community we grant back out to community organizations to provide screening, diagnostics, treatment, surgeries, and other forms of direct help. These support services are for uninsured and underserved women and their families. Twenty-five percent of our fundraising goes to our headquarters, which is then invested in global research to find the cure for breast cancer. The majority of funds raised here, stay here.

We have invested millions in the State of Nevada, particularly this year. The southern Nevada affiliate just issued $800,000 in community grants. The majority of these grants will go toward breast cancer treatment. We are able to provide wonderful life-saving services. As has been mentioned many times, early detection and effective treatment are the absolute best tools for surviving any cancer.

In Nevada, the CDC grant provides funds for our state's Breast and Cervical Cancer Early Detection Program. It is called the Women's Health Connection. This program provides breast cancer screening, outreach, and case management services for women without health insurance. Since its inception in 1997, the Women's Health Connection has served nearly 35,000 women. In 2008, 3,600 mammograms and 6,000 pap tests were provided to age-eligible women who do not have health insurance and meet the program's income guidelines. On average, the program diagnoses about 85 cases of breast cancer each year and 46 cases of cervical cancer. This program is invaluable for uninsured women in Nevada that are facing a cancer diagnosis. Komen for the Cure provides services such as screening for women who are not age-eligible for Women's Health Connection and provides financial assistance for those going through treatment. Support services for breast cancer patients are available throughout all of Nevada. Our work in the community could not be possible without the Women's Health Connection and also the Medicaid option for breast and cervical cancer treatment.

These programs have literally saved thousands of lives, but there are some challenges. The current funding level for the Women's Health Connection program allows the program to cover less than one in ten eligible Nevada women. So 90 percent of the women who are eligible are left without access to screening through this program. Unlike many other states, Nevada does not contribute funding to the state program, which limits the availability of this resource and, in fact, forces providers to establish waiting lists for eligible women to be seen. Additionally, Nevada is one of only 21 states that have selected the most restrictive coverage option through the Breast and Cervical Cancer Prevention and Treatment Act. This option provides full Medicaid coverage to women for their breast or cervical cancer treatment, but only if their screening services were provided by Women's Health Connection and they meet additional eligibility requirements. So, if diagnosed with breast cancer, certain low-income and uninsured women are unable to receive Medicaid-funded treatment based solely on where they were screened. If a woman is diagnosed at a non-Women's Health Connection provider clinic, she will be ineligible for Medicaid treatment coverage. This concern regarding access to effective breast cancer treatment has been further exacerbated by the recent closure of UMC's outpatient oncology program.

As part of my role with the Komen Southern Nevada Affiliate, I provide patient navigation and assist women with finding screening services all the way through their treatment. Since the closure of UMC's outpatient oncology program, we have identified at least 15 women that have been diagnosed with breast cancer and have been left without options for treatment. Any delays in their treatment can and does affect their prognosis and their chances of survival. To help fill this gap, the Komen Southern Nevada Affiliate has awarded a $500,000 grant for surgery, chemo, and radiation treatment. However, our best estimates are that even with significantly discounted rates, this funding will only cover care for about ten breast cancer patients this year.

Without oncology services in southern Nevada, the hundreds of low-income, uninsured, and indigenous cancer patients are being left with no options. They are being given a death sentence. They have nowhere to turn. We have to protect every woman's chance at survival. Their fight is our fight.

The State of Nevada has a cancer control plan. It is a solid plan and we are here working together with the Council to start saving lives now. We challenge Nevada to change policy to eliminate gaps in screening and treatment services and ensure equal access to cancer care for all. Thank you for recognizing the importance of cancer programs and policies and taking the time to be here today.

Assemblywoman Parnell:
I have a rather odd question, but I think a lot of us have been in this position. I get so many things in the mail for donations and I always donate, but my priority is always to donate either in the Carson City area, because that is where I live, or to know that I am donating to one of the organizations that is in-state. Is there any way for any of us to be able to identify what stays here locally and what does not?

Stacey Gross:
Sure. If you make any donation to Susan G. Komen for the Cure, it will be sent to either the southern Nevada or northern Nevada affiliate. Neither affiliate does direct mailing. So, if you are receiving direct mailing, it is probably coming from our headquarters, in which case your donation will be allocated to research programs through them.

Assemblywoman Parnell:
Because I live in Nevada and have a Nevada address, do they send some of that donation back to one of the two affiliates?

Stacey Gross:
It is a small percentage, so we always encourage donors to really be aware of where your money is going and how it is being used. If you donate to one of the local affiliates, 75 percent will stay in our service area.

Assemblywoman Parnell:
I think that is so important for so many of us. I will receive mail that says Carson City for one of the cancer drives but then their address is in Maryland. I am never really sure. So, is it best to go down to the local office and write a check and do direct contributions so that we can maximize the amount the local affiliate receives?

Stacey Gross:
Absolutely. Both of our websites, northern and southern, are set up for that as well.

Assemblyman Hambrick:
I listened very attentively to the presentation. My wife is a breast cancer survivor so I have a particular interest in this matter. I will listen equally attentively to Mr. Musgrove's presentation, since I am a prostate cancer survivor. These issues have to be addressed.

Chairwoman Smith:
Are there any questions from the Committee?

Assemblyman Hardy:
If I understood correctly from your presentation, if we find somebody who went to a "free" clinic for a mammogram and she was found to have a suspicious lesion that turned out to be a cancer, she would not be eligible for Medicaid. But, the good news is that we do not have enough Medicaid funding to treat the people who we already have under Medicaid. Is that what I am hearing?

Stacey Gross:
I do not know if that is good news. If they are not eligible for Medicaid, they are likely not going to find treatment, at least in southern Nevada.

Assemblyman Hardy:
So what I heard you say about Medicaid is that we have capped the number of people who can be treated under Medicaid?

Stacey Gross:
No. We estimate that ten individuals will be served through our Komen grant in southern Nevada this year. The way the Medicaid treatment option for breast and cervical cancer works is that women are only eligible to be covered by Medicaid for their breast and cervical cancer treatment if they are diagnosed through a Women's Health Connection provider. So, if they go to the wrong clinic and are not enrolled in the program at the time their biopsy is done, they will not be eligible for the treatment option.

Assemblyman Hardy:
So, do we have enough money in the Medicaid budget to treat all of the people who go through the appropriate clinic to get their biopsy done?

Stacey Gross:
That I cannot answer. I know that, right now, those who are diagnosed through the Women's Health Connection are fast-tracked to Medicaid and are being treated.

Assemblyman Hardy:
You have not turned anybody away?

Stacey Gross:
We are not turning them away at this time.

Assemblyman Hardy:
If they are eligible, they get the treatment if they go to the right place first?

Stacey Gross:
That is right.

Assemblyman Hardy:
So, do we have an obligation to discourage people from going to a free clinic to get their mammogram done or from getting a free mammogram if it is not done at the right time in the right way?

Stacey Gross:
I do not think we ever want to discourage anybody. Getting a mammogram will not make them ineligible. Having an ultrasound or an MRI will not make them ineligible. At the point of biopsy, they need to have their biopsy conducted while they are enrolled in the program to ensure that they will receive the Medicaid treatment option.

Assemblyman Hardy:
So, if they go to a free clinic to get their free mammogram and there is a suspicious lesion, and they are Medicaid eligible, income-wise or otherwise, it would behoove them to be told at the same time they get their report that they need to apply now before they get their biopsy.

Stacey Gross:
Absolutely.

Assemblyman Hardy:
Do we have a list of those places?

Stacey Gross:
We do. There is a list of Women's Health Connection providers available on the health section of the Nevada State website.

Chairwoman Smith:
I see that Mr. Duarte is in the audience. We might ask you to provide a quick note to the Committee about the Medicaid situation with breast cancer treatment that we have been discussing. Is there enough money in the budget to treat the women who are diagnosed?

Lewis Musgrove, Chair, Governor's Task Force on Prostate Cancer, Health Division, Department of Health and Human Services:
[Distributed outline of testimony (Exhibit H).] I am a 17-year prostate cancer survivor. I also lead a support group called Us Too in Las Vegas and we are the largest prostate cancer support group in the United States. There are 330 chapters throughout the United States, and I served two-and-one-half years as Chairman of the Board. I have a personal interest in prostate cancer.

In 2003, a woman here in Carson City, whose husband was dying of prostate cancer, happened to be a good friend of Governor Guinn. She and I went to the Governor, and the Task Force was started. We were unfunded but we were able to do a lot of talking in the community. In 2005, we received a grant for $50,000 from the Governor. We were then able to put together brochures and a banner for health fairs, et cetera. We have a website and an 800 number, and provide a 211 number. If someone dials 211, they are sent either to the website or to the 800 number. We put out a Father's Day "letter to the editor," which made more sense than doing a news release. We also put on a wellness exposition in Las Vegas.

In 2007, we had the opportunity, thanks to Senator Coffin, to get a bill that mandated insurance coverage for prostate specific antigen (PSA) and digital rectal examination (DRE). The PSA is a blood test that goes to the pathologist and has a number assigned to it. The number should be below one. That same vial can also be used to check cholesterol. Then, Senator Titus came up with the Gardasil idea, so the two of them were put together as Senate Bill 409 of the 74th Session. It was passed and signed by the Governor and became law. We did not realize that the monies that were left over in the two Task Forces would not get carried forward. Those funds went into the State General Fund. Now, we have an insurance bill on the books that no one knows about and there is no money to advertize it.

We wanted to use the excess money from the Task Forces to send letters to all general practitioners and family physicians so they would be aware that the insurance companies would have to cover those procedures. Secondly, we wanted to put out another Father's Day letter to try to help fulfill the mission of the Task Force to raise awareness of prostate cancer by men in the State of Nevada. In that letter we would try to inform them that prostate cancer is not a matter of "if" but a matter of "when."

I would like to read a brief statement about prostate cancer from Dr. William Catalona of Northwestern University: "Prostate cancer is an insidious disease that arises silently. It passes through a curable phase silently and becomes incurable silently. If you wait for symptoms to signal its presence, it is too late to cure it."

If you check with the United States Prevention Services Task Force and the CDC, they do not recommend that screenings be done. What we need to do is establish a baseline PSA on an annual basis, record it, and do not allow your physician to say it is normal. We do know that the change in the number is more important than the number itself. If the number changes more than one point, something is happening in the prostate and you need to go to an urologist to find out what is going on. There are several other things that can cause the number to rise; not just prostate cancer. The important thing is testing on an annual basis. You will then have control of the situation. Early detection is important; it saves lives.

Chairwoman Smith:
Are there any questions from the Committee?

Assemblyman Stewart:
I want to disclose that I am a long-time friend of Mr. Musgrove. Also, I get my yearly PSA test and I commend Mr. Musgrove for his passion and continuation of doing good works.

Lewis Musgrove:
I would like to add one thing. We did not talk about when to start getting PSA tests. We believe age 40 is the time to start this annual PSA/DRE baseline, except for high-risk patients who should start at age 35. High risk is if you are an African-American, if you are a bloodline relative of a prostate cancer survivor, and those who have an indeterminate family history. If a person has been adopted, they would not know their family history.

Mary Guinan, State Health Officer, Health Division, Department of Health and Human Services:

I am here to give an update on the Fallon leukemia cluster. In early 2000, we had a report from the physicians at Churchill County Hospital which was conveyed to me through an Assembly member, Marcia de Braga. She told me that there were a number of leukemia cases and they were very concerned about the increase. The Health Division initiated a study and looked at all of the records and at that time there were four cases. [Distributed a CDC timeline (Exhibit I).] Two of the cases were diagnosed in 1999 and two in early 2000. The Cancer Registry alerted us to the cluster. We found that in Churchill County we could expect one case of acute lymphocytic leukemia in the county every five years. We had already had four cases within a one-year period. There was a preliminary investigation done but during that time period there were more and more cases being reported. It was extremely unusual to have a cluster of leukemia cases recognized while they were happening and not by looking back at data. It was very important that this particular cluster be investigated.

Usually, clusters of cancer are investigated many years after it happens. We know very little about children's cancer, but the cases of acute lymphocytic leukemia occur between the ages of three and five years. We assume that there is an environmental agent that contributes to the cancer. The idea was to try to interview all of the patients' parents and families and find out about any exposure. The hypothesis at the time was that this might have occurred in utero because the age of onset was three to five years and because it is a long incubation period pursuant to the exposure to the agent and the disease manifestation. We tried to find out what the mother had been exposed to and what the child had been exposed to.

We found nothing in the preliminary investigation and the cases continued to be diagnosed. [Distributed a summary of findings from the CDC (Exhibit J).] The Centers for Disease Control and Prevention were very reluctant to investigate the cases because they have done many investigations and have not found anything as a result of those investigations. With the help of Senator Reid, we convinced the CDC that this was a very important epidemic because we were finding it in the acute phase. We were much more likely to be able to identify the cause if there was an environmental agent. The CDC did one of the most extensive investigations they have ever done for a leukemia cluster.

There were a number of different studies that were done including collecting samples from the patients and their families, their homes, and selecting a control group that did not have the cancer. The results of those studies are in the *Cross-Sectional Exposure Assessment of Environmental Contaminants in Churchill County, Nevada, Final Report* (Exhibit K). In summary, there was found to be a general elevation of tungsten in the families and the children, but it was also found in the control group. It was unclear what that meant, but it was very important that we try to use that information in some way to investigate further.

Their next step was genetic testing using tungsten on the families, knowing that tungsten inhibits certain enzymes. They looked at the genetic frequency of various enzymes that were in the metabolic framework of tungsten and found something peculiar in that the cases did have an unusual locus on a gene for this enzyme. That is the only result that we have indicating that there might have been a genetic susceptibility. No causative agent or agents were found. It is extremely important to note that these investigations were some of the first investigations in which data was gathered so that this type of research can be done. It is called hypothesis generating.

There was a United States Senate hearing in Fallon subsequent to the investigation and there was testimony from experts from across the nation. They asked what could have been done. The question that came up after the Fallon leukemia cluster was, "Are other diseases increased in Fallon"? We did not know the answer to that because we do not collect data on other diseases. The recommendation was to develop a system for chronic disease data collection in Nevada. The second recommendation was that we need to study other environmental agents that we do not currently suspect. We need to have a data base for all kinds of toxic substances within Nevada. Radioactivity was also looked at, but no signs of that were found.

There is no exposure data in the Cancer Registry. There is only the diagnosis that the patient has cancer, but it is unknown what happened to those patients before diagnosis. One of the things that is lacking in Nevada, for example, is data regarding exposure to radiation in southern Nevada because of the atomic testing. We know that many people were exposed, but there was no registry for that exposure. We understood that we needed a new systematic way of collecting data so that we could try to solve those problems.

With regard to your question, Chairwoman Smith, about why the Cancer Registry did not identify the epidemic, the clinicians were much more alert. They knew something was wrong and they told us before the diagnosis was even made about the cluster. Cancer registries are not designed to find clusters. They are designed to look at incidents and prevalence of cancer.

Chairwoman Smith:
I guess we were fortunate because we were seeing this happen in real time.

Mary Guinan:
That is right. We had an acute cluster that was new and people were alive to talk about it. We found nothing specifically that we could identify as a toxic exposure that might have been the source.

Chairwoman Smith:
I was curious about what the final information was with the Fallon cluster. Are there any questions from the Committee?

Assemblywoman Spiegel:
Was there any communication between Nevada and Sierra Vista, Arizona, about the childhood leukemia cluster that they had there, to see if there were any commonalities either in the presence of arsenic or tungsten in the water, or the genetic component?

Mary Guinan:
There were communications from different agencies. Their cluster was identified later and there was some problem with the data, and their understanding at the time was that there was no cluster. I understand there are ongoing studies with tungsten both in Arizona and Nevada. One of the things that we were unable to do, but is very important that we try to do in the future, is that we needed samples of the tumors. We do not have a treatment center in Nevada. The patients went to different hospitals to be treated. If we could have done genetic analysis of the tumors and found similarities in the mutations in the cancer cell, we would have had evidence that there was one environmental exposure that caused it.

Assemblywoman Parnell:
I remember the hearings in 1999. I would like to thank the physicians in the area, but also thank former Assemblywoman Marcia de Braga because she got on the problem immediately.

Chairwoman Smith:
I think it was actually 2001, and I was here. We had a big hearing.

Julie Tholl DeJan, Executive Director, Angel Kiss Foundation, Reno, Nevada:
[Distributed Angel Kiss Foundation 2008 Annual Report (Exhibit L).] Our mission is to help all families of children with cancer in northern Nevada and the eastern Sierra region by providing immediate and continuing financial assistance and emotional support. We began in 1990 with the death of five-year-old

named Jared, who passed away from leukemia. The foundation wrote its first check in April 2000. We serve families in northern Nevada and the eastern Sierras. Our southern border is Tonopah, and we go west as far as Susanville, Quincy, and Portola.

By the age of 20, 1 in every 330 children is diagnosed with cancer. About 12,500 children are diagnosed each year in the United States; it is the number one disease-related killer of children. We do not have a cancer treatment facility here in northern Nevada for pediatric oncology. Most of the families travel out-of-state for at least their initial induction phase. Depending on their diagnosis, they may travel for their entire treatment. It adds a huge burden for these families to what is already emotionally and financially devastating. The travel expenses each day easily reach $200 and they stay out-of-state for weeks at a time for treatment and still have to balance two families, one at home and one away.

One of the nonmedical complications is remaining in school. Many children cannot go to school because their immune systems are compromised. There are sometimes problems with job retention. Future health concerns of the child are also a problem. The siblings are sometimes concerned about their own health. There are extra expenses traveling to and from treatment and extra expenses as discussed for inpatient treatment and living closer to the treatment facility. There is also depression, changes in appearance, fear, pain, and burden on the family. There is a lot that goes on.

I have an example of a hospital bill from Oakland, California, for a two-week stay. The family did not have health insurance. The child was diagnosed just after they lost their insurance. It totaled $172,480. Angel Kiss helps in this area because we have several programs to address community need. First, is our client assistance fund. We also have a formal support group which we just started along with a Kids Club, holiday programs, awareness day participation, and a resource network with other organizations.

In 2002, we assisted 14 families in total. Since October 2008 we have received 18 new applications. We have experienced a 400 percent growth in services since our inception. In 2007, we increased our family assistance allotment from $2,000 per family per year to $3,000 per family per year. We just recently expanded our programming to include a Kids Club and a support group, purely based on community need. We also instituted the Northern Nevada Childhood Cancer Collaborative, which is a group of other support organizations that come together quarterly to discuss issues.

All of the money given to our organization stays in our local community. We have served over 210 families in our nine-year existence and provided over $610,000 in direct financial assistance to these families. Our client assistance fund is available to families through a single-page application and a simple confirmation of diagnosis and treatment. We have no financial criteria. We do not reject a family because they have too much income. Basically, when the child is diagnosed, the family is accepted into our assistance program. We have immediate assistance. Within two hours of diagnosis, I have helped families that are out-of-state and need some money for lodging or food. We can do that very quickly for them. The $3,000 per family per year is an unrestricted source for them. They can use it as it best suits their family, whether it is a mortgage payment, medical bills, or whatever is specific to their family. After the child is out of treatment, if they still have the $3,000, they have to use it for follow-up care, medical costs, and travel expenses.

Prior to this year, we were solely financial based. We asked our families what they needed, and they told us they needed emotional support programs. We created the support group and the Kids Club to fill that need. There is also research that shows why we should have emotional support programs. Our support group meets monthly, and there are no fees for participation. They are separated into three groups: the adults are facilitated by a local marriage and family therapist. The teen group is facilitated by the psychologists from Children's Hospital, Oakland, California, who we bring into town once a month. The small children are facilitated by the child life educator from Renown. These programs create a connection between Oakland and Reno when a family comes back to continue their treatment here. This is a fully collaborative effort with The Keaton Rafael Memorial Childhood Cancer Board; we share the expense and we share the organization of the group. We do informational segments, emotional support, and socialization opportunities.

The second group that we started is called the Kids Club and it meets monthly with no fee. It is a kids-only, no-parents-allowed situation, and the children are really excited about it. Many children lack social skills due to the time away from school; time they have missed due to treatment. This gives them an opportunity to bond with children their own age and children who have experienced the same things. It is a chance to just be a child, where their hair loss and feeding tube are not looked at oddly because the other children have all experienced it. They do movie nights, pizza parties, arts and crafts, and outings.

Our funding is primarily driven by grants. Secondary to that is the one fundraising event that we have each June. There are also community fundraisers and private donations. Our annual budget is about $264,000.

As we look forward to our next nine years, we want to increase the allotment we provide to families and evaluate and improve on the emotional support programs that we just started, as well as participating in bringing the Children's Hospital to northern Nevada.

Chairwoman Smith:
I want to stress the statistic of 14 families being assisted in all of 2002, and 18 new families just since October 2008. The numbers are staggering. One of the things I have learned is the urgency. The children are diagnosed out of the blue and it turns a family's life upside down.

Are there any questions from the Committee? I see none.

Jennifer Bradley, Executive Director, Candlelighters Childhood Cancer Foundation of Nevada, Las Vegas, Nevada:
I would like to introduce a very special woman. She is here to share her story. Her name is Alexa Walker and she is 17-years old. I would like to let you know that I am happy to be a part of the Nevada Cancer Summit.

Alexa Walker, Private Citizen, Las Vegas, Nevada:
I am a 3-year childhood cancer survivor. I was diagnosed in January 2005 with a rare bone and soft tissue cancer. For treatment of my cancer, I had extensive spinal surgery, 11 months of chemotherapy, and 2 months of radiation. The majority of my treatment was here in Nevada at Sunrise Children's Hospital. But when it came to the radiation portion of my treatment, I had to travel to St. Jude's Hospital in Memphis, Tennessee, which was very hard for my family, but they did not offer the kind of radiation that I needed here in Nevada. When we needed to travel there, Candlelighters helped us out tremendously, both financially and emotionally, and they still do today.

This summer I am going to be facing another surgery because of some side effects from the treatment, and Candlelighters will again be helping us out. They also introduced me to my best friend, who, just this past week, was rediagnosed with pancreatic cancer. It has been a very hard week for us. I know Candlelighters will be helping her with her transportation. She has to go to the City of Hope in Los Angeles, California, to get treatment.

Chairwoman Smith:
We are so glad that you have done well, and we wish you the best of luck with your surgery this summer. We are sorry to hear about your friend. We will keep you and your friend in our thoughts.

Jennifer Bradley:
Alexa is an example of the truly amazing teens and kids that we see at Candlelighters. They provide each other with a lot of support. Alexa's friend has to travel to Los Angeles by ambulance to the City of Hope. Our hearts go out to her. These past two months we have lost four children and two babies. We have a little boy who also has taken a turn for the worse, so we made sure we had a big party for him at the hospital, and when we celebrated Christmas and his birthday, we made sure his whole family was there.

We are very similar to Angel Kiss and it is amazing what they do in northern Nevada. We try to do the same for our families here in southern Nevada.

[Spoke from written testimony (Exhibit M).]

We offer financial and emotional assistance, as well as quality-of-life programs which can include support groups, such as our Teen Scene. We have bereavement counseling. We go to the hospital every day and have movie Mondays, fast food Fridays, and art and music therapy at the hospital. We try to be there for the whole family. We are very excited because we just started a pen-pal program with Big Brothers and Big Sisters.

Our goal is to ensure that no child or family must fight the uncertain world of cancer alone. When your child is diagnosed, it is overwhelming and your life turns upside down. Our staff is on-call full-time. We usually get a call from the hospital or directly from the doctor's office and we make sure we are there no matter what time of the day or evening. We offer case management, help them navigate to other resources that may be available financially, or just provide emotional support. There are many families that cannot work. They like to be next to their child to make sure the child receives his treatment; however, due to the high medical costs, as well as losing work time, there is a huge financial burden. Candlelighters is there. We have an emergency assistance program. We pay their rent, utilities, mortgage, and whatever we can do to lessen that burden. We also help with medical co-pays. Some prescription medicines can cost up to $1,000. There might be a co-pay of $2,000, which is very difficult for families. We have no income guidelines. Our cap for financial aid is $5,000 per family currently; that does not include funeral expenses, which we also help with. We hope that we can extend that cap. Some children are in the hospital for three months at a time. This can be an extreme hardship, but we also help with travel for treatment.

Again, brain tumor is the number two cancer and it is something that we do not treat here in Nevada. Many of our children have to go out of state for that treatment. We will pay for airfare, lodging, and food. We had a little guy who was at the City of Hope for a year and a half receiving treatment, and we were able to work out a special deal with City of Hope to provide lodging for the family.

I would like to reiterate some of the pediatric statistics. Each school day, 46 children are diagnosed with cancer. It is the number one killer of children, more than cystic fibrosis, muscular dystrophy, asthma, and AIDS combined. Two-thirds of pediatric cancer survivors will also have a health effect later in life. We try to work on those late-term effects. We have an excellent survivorship program: we provide college scholarships for children, and try to be a full resource for the whole family.

We also offer counseling for families because this is an extremely emotional and difficult time for them. We are proud of what we do for the families. We are in jeopardy of having to cut our emergency assistance programs due to lack of funds. We want to continue being a good resource for the State of Nevada.

Chairwoman Smith:
Are there any questions from the Committee? I see none.

This concludes the presentations today. Everyone on this Committee has been impacted. Whether the patient is 8 months old or 80 years old, they are all victims of a very tragic disease. They have varying needs, and the work that you people do is invaluable. It is the collaboration and contributions that you make that help everyone.

We will open the hearing on Assembly Bill 269.

Assembly Bill 269: Makes various changes concerning the provision of health care to certain children who do not reside with a parent or legal guardian. (BDR 38-146)

Mark Fiorentino, representing Nevada Partnership for Homeless Youth, Las Vegas, Nevada:
I do not know a lot of the details of this bill, but I am very supportive of it. I promised Chairman Conklin that I would introduce it to you briefly, tell you what I do know about it, and try to answer questions to the extent that I can.

There are numbers of children who need help that do not have a safe place they can call home for one reason or another. Either they do not have parents or legal guardians, or it is not safe for them to be at home. This bill would go a long way towards helping those children by making them eligible for certain health benefits. This bill is relatively simple and straightforward.

Section 1 of the bill requires the state's Medicaid plan to cover children who do not reside with their parents or legal guardian. Section 2 extends some of the existing limitations on liability in terms of getting the consent of the parents for treatment for these minor children. The obvious reason is that these children either do not have parents or legal guardians, or it is not a safe situation for them to get help from their parents.

Chairwoman Smith:
If I remember correctly, we have already passed legislation that provides this kind of coverage for children who are in foster care. This bill would fill that gap for the children who are not in foster care, is that correct?

Mark Fiorentino:
That is correct.

Assemblyman Hardy:
I have this vision of somebody doing something with children and I am looking at this bill through the eyes of Oliver Twist. I wonder where the court is in this, or would it make more sense to have a societal figure rather than an adult?

Mark Fiortentino:
That is probably a good question. In the cases that I have dealt with through the Partnership for Homeless Youth, there is not a court involved. These are children who are not adjudicated through the court system. I know what the intent of the language is and I believe we can fix it and tighten it up to address your concerns. The intent is to allow organizations like ours that are providing assistance to children to provide the role that is contemplated in this bill. I think that is what was intended by that language.

Assemblyman Hambrick:
Have you seen the amendment offered by Planned Parenthood?

Mark Fiorentino:
I have not.

Callyce Carroll, representing Nevada Partnership for Homeless Youth, Las Vegas, Nevada:
I am a former homeless youth. I would like to share some of my experiences as such. When you are on the street, a little thing like a cold can become a big issue because you cannot go to the hospital or get treatment. It could get worse. In my experience, I got the flu and developed a fever which got worse because I could not go to the hospital. I ended up going to the hospital, and in doing so I received a $12,000 bill. This affected me in the future when I turned 18. I wanted to get an apartment, but my credit was bad because of the medical bill. I have friends from when I was out on the streets who are still there. When they get a minor cold, it becomes more than that without health care.

Chairwoman Smith:
Are there any questions from the Committee?

Assemblyman Cobb:
Would this law change any of the rules regarding minors seeking abortions?

Mark Fiorentino:
To the best of my knowledge, no, but that question is way over my head.

Chairwoman Smith:
Probably Mr. Duarte would be best to answer that question.

Charles Duarte, Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services:
As this bill was being drafted, we talked with the bill drafter to make sure that the intent of this bill is to codify policy which is already in place at the federal level and in our state program. Any adult could apply on any minor's behalf. A minor cannot apply on her own because, as I understand it, federal regulations require that the individual who applies for Medicaid is able to enter into a contract, but a minor cannot contract. This is a provision in our policy that already exists, whereby any adult can make an application for Medicaid for a minor child. Our understanding is that this is just codifying what exists in federal and state law.

Chairwoman Smith:
So you are doing this now to codify it in the law?

Charles Duarte:
Yes. With respect to the other provision of any health care benefit, we do not necessarily pay for abortions under Medicaid. There are actually two pieces to this bill: one is the application for Medicaid and, as I have already explained, this bill just codifies what already exists in policy. The other aspect of this bill, which we do not have any comment on, has to do with the waiver of liability by the professionals or facilities that treat a child. That is a separate aspect and is not related to Medicaid services.

Assemblyman Hardy:
I am trying to envision different scenarios and one is the runaway who has not been abused, who has depression, and is estranged from the family, but not because of the family's "fault." The child eventually returns to the family after having had any adult give permission for something to be done, and then the liability reverts to the family. I do not know what the answer is.

Charles Duarte:
My comments are more directed at the eligibility component of this bill and what it seeks to do in that regard. You raise a good concern about liability. I am not an expert in the field of medical liability.

Chairwoman Smith:
Are we seeing any problems that we know of? Or, would you know about problems that are out there if this program is being utilized currently?

Charles Duarte:
I might ask the Chief of Eligibility and Payments of the Division of Welfare and Supportive Services to comment. I am not aware of any problems. There are so few children who come into Medicaid as a result of this. Perhaps there are six or seven children a year applying through a process that the Division of Welfare and Supportive Services has worked out with the organization that is putting this bill forward.

Assemblywoman Leslie:
Is this a policy that was done through a state plan amendment or has it always been done that way? Is there a need to codify it if it is part of the plan?

Charles Duarte:
My understanding is that it already exists under federal policy and the state is given some flexibility by the federal government to establish policies that are consistent with state laws that define when a child reaches majority and is able to sign a contract. Different states have different age limits as to when a child can be considered capable of signing a contract.

Assemblywoman Leslie:
So the question to the bill's sponsor is, has it been a problem and, if it has, is it because they do not understand how to access Medicaid? Or, what is the real issue?

Mark Fiorentino:
I am not sure. Let me get with Chairman Conklin and tell him what your concerns are and I will volunteer my time and capabilities to try to resolve them if we can.

Chairwoman Smith:
There are some technical issues that may need some work. We are talking about a small number of people. We want to be sure we have all the information correct.

Charles Duarte:
I do have one more comment. I want to make it clear that this is not a new program; there is no fiscal impact associated with this.

Elisa Maser, representing Nevada Advocates for Planned Parenthood Affiliates, Reno, Nevada:
We have five health clinics in Nevada and we offer health care to thousands of women and men every year. We are in support of A.B. 269 as written. One of our major priorities is increased access to health care. [Distributed a proposed amendment (Exhibit N).] If this amendment in any way jeopardizes the bill, we would certainly withdraw it. Of course, we think that all parents want to know exactly what is going on in their children's lives and we understand and encourage that. We have young people who come to our clinics and sometimes it is not safe for them to involve their parents. Some of these children are homeless and are in situations in which they are in conflict with someone in their family, possibly a boyfriend or stepfather. Most parents would like their children to be safe even when they cannot go to them.

The amendment that we are discussing would encourage the minors to communicate with their parents but not require it. The other issue that this bill raises to me is that we are creating two categories of minors getting health care. If we treated a young person who had Medicaid, we would not be required to get consent to communicate with his parents. If he did not qualify for Medicaid, we would be required to get consent to communicate with his parents. We would like to see it consistent. Again, we would like to see this bill pass. We would withdraw the amendment if it threatens passage.

Chairwoman Smith:
Have you worked with the sponsor on this amendment?

Elisa Maser:
We just had a very brief opportunity to talk about it. He was concerned that it might jeopardize the passage of the bill. It sounds as if there are some clarifications needed. We would work with the sponsor to make sure that we have the best opportunity for passage.

Chairwoman Smith:
I would encourage you to talk to the sponsor.

Assemblywoman Mastroluca:
I would like to disclose that I worked with the Nevada Partnership for Homeless Youth for one year and worked with these children. I understand what you are trying to do with your amendment, but I caution you because this could be extremely dangerous to these children. Some of these children have seen things that no child should see. Some of these children have been involved in things that no child should have knowledge of. Adding this piece that says you are not required to obtain consent of the minor to communicate with the parents is scary. I fear for the children who are in hiding because they need to be. I know there are some children who have run away from home because they are mad, or they did not get their way, or they feel they are being treated unfairly because the neighbor child has something better than they do. I have met those children, too. Nine times out of ten, those children go back home. If they are the children who are being beaten and ostracized for choices that they have made in their lives, or the children who are struggling because mom brings home the seventh stepdad, those are the kinds of children who need this kind of protection. I think there is a better way to do it.

Assemblyman Hardy:
I have serious concerns. If we are trying to protect children who are being abused, we have an obligation as all adults do to call protective services. That is the law. I am puzzled: if we are doing this to protect the children, then why are we not calling protective services?

Chairwoman Smith:
We will sort all of that out. We will bring this all back together.

Is there anyone else wishing to testify on this bill? I see none. We will close the hearing on A.B. 269.

We will open the hearing on Assembly Bill 326.

Assembly Bill 326: Revises provisions governing controlled substances. (BDR 40-558)

Assemblyman Mo Denis, Clark County Assembly District No. 28:
Last session I brought forward a bill because I had some constituents who had become addicted to prescription narcotics. I had a mother come forward whose daughter had died. She had become addicted to prescription narcotics, had been able to detox, and to get off the drugs. But the daughter had a second accident and the doctor prescribed 200 pills for her pain. Within two days she died from an overdose. We made some changes last session that allowed for the opportunity to help.

During the interim, the *Las Vegas Sun* had a multipart feature on prescription narcotic abuse. I would like to highlight some of that article. It states that Nevadans consume about twice the national average of several prescription pain killers, making us among the most narcotic-addled population in the United States. The consequences are deadly. More people in Clark County die of prescription narcotic overdoses than of overdoses of illicit drugs or from vehicle accidents. In 2006, Nevadans were the number one users, per capita, of hydrocodone, better known by the trade names of Vicodin and Lortab.

Assemblywoman Sheila Leslie is quoted as saying, "It is important to understand that surrounding the rise in prescription narcotic use and abuse, Legislators may need to take a closer look at the law that prevents analyzing the state's highest prescribers."

The reason I brought this bill forward is because I think we need to do that. We need to take a closer look at what is going on and see what else we can do. With that, this bill does several things. In section 1, it provides for the State Board of Pharmacy to be able to designate what is a controlled substance in a timelier manner. I have some of the State Board of Pharmacy members here and they can, perhaps, speak to that. This is one of the sections where we have received amendments.

The second part is on page 4, lines 24 through 31, where it talks about the database. I should explain for those of you who have not heard this before, there is a database that the State Board of Pharmacy maintains of all of these prescription narcotics so that when someone prescribes it, it will go into this database. A doctor could look it up and find out what is going on. If a doctor suspects that someone is abusing, he can run this report and it will give him a list of all of the prescription narcotics that person has received prescriptions for. He would be able to see if there is abuse. This bill would make it possible to include contact information for the people that have access to the database. They could analyze the data and provide some accountability for the doctors.

Page 5, lines 11 through 16, says anyone who has access to the database would receive some training. In this case it would be provided online. One of the concerns that came up was there are some doctors who do not use the database because they remember the old days when you would put your request in and you would not get your answer back for three days. That was not helpful because the person could be gone by that time. Now it is fairly instantaneous. This would provide the opportunity for anyone who is going to prescribe to have the ability to know what is happening.

The language in lines 25 through 36 talks about the Legislative Committee on Health Care conducting a study. They do not have to spend a lot of money, but can use it as an opportunity to look at this issue of prescription narcotic abuse.

Chairwoman Smith:
Are there any questions from the Committee? I see none.

Joanee Quirk, Program Administrator, Prescription Controlled Substance Abuse Prevention Task Force, Nevada State Board of Pharmacy:
We have collected data since 1997 on all controlled substance prescriptions dispensed in the State of Nevada. The database is used primarily by practitioners. If they have a new patient, suspect a current patient may be a substance abuser, or have a patient that goes to multiple doctors and multiple pharmacies, they can now go into our system 24/7 and request and receive a report on that patient. We want the pharmacies to be able to do the same thing. The prescriber will write the prescription and the patient will take it to a pharmacy. The pharmacy, being a closed system, can look at their own prescriptions for that patient, but they cannot look statewide or citywide for that patient. We would like to give that access to the pharmacies.

Approximately 65 percent of the pharmacies in Nevada are chain stores. Even though they have a closed intranet system between their own stores, we would like them to have access to our unsolicited reports. Right now, they are mailed to the pharmacies, but I would like to be able to email them and let them know there is a potential problem with one of their patients. They could then log into our system and collect the data about that patient, then make an evaluation on what to do with the patient and the prescriptions that the patient has been receiving. Hopefully, we will be able to get the practitioner and the pharmacy to speak together with the patient about the possibility of substance abuse.

As far as the system itself goes, it is antiquated and I am looking at a new piece of software. It takes several months to get new contracts through purchasing and the Board of Examiners. This system is run by federal money and, as soon as I receive the federal money, I have to start spending it or I will have to give it back. It is very specific and does not go into the General Fund. It is only for the prescription monitoring program.

Chairwoman Smith:
Is section 1 related specifically to carrying out this program, or is this a general provision for the work that you are doing?

Joanee Quirk:
It is specifically for the work that I am doing with the Controlled Substance Task Force.

Chairwoman Smith:
Are there any questions from the Committee?

Assemblyman Hardy:
In section 1, are you seeking to be authorized to expend the money that you have?

Joanee Quirk:
There are four specific vendors for this particular type of software. I have already gotten prices for their different pieces of software and the requirements that we have. I would like to get a waiver from going through the bid process. The new vendor has enhanced their system and I will be able to retrieve data once a night instead of once a week, along with filtering some of the specific prescription information. The contract is $137,000 for two years.

Assemblyman Hardy:
Does that include the maintenance of . . .

Joanee Quirk:
It includes enhancements and maintenance and also includes the actual executable source code. If I ever get into a position where the vendor does not want to enhance the program anymore—or wants to charge me for enhancements—I can pluck it out of the vendor's system and bring it back to our information technology system and have it maintained and enhanced in-house.

Assemblyman Hardy:
So this may not be an ongoing thing? The waiver for the bid is one thing. I want to know if we have to write in "and may expend money" because sometimes we allow you to get it, but do not allow you to spend it. Does this allow you to spend it as well as acquire it?

Joanee Quirk:
We are self-funded. We do not get any money from the state, if I understand your question correctly.

Assemblyman Hardy:
We do not need to put in anything that says you can spend the funds?

Joanee Quirk:
Correct.

Assemblyman Hardy:
In section 7, lines 24 through 30, who puts in the name of the person, the physical address, the phone number, and the person maintaining their electronic mail address? Who does that? Is it the pharmacist or the practitioner?

Joanee Quirk:
I am unclear about your question. Are you asking about the person who is obtaining the information or if it is the actual patient information? If it is the patient information, it comes from the pharmacy. If it is the practitioner's information that I need to access, I have a separate database that includes all the information about a practitioner and a pharmacy. I will probably have to add email addresses to the database.

Assemblyman Hardy:
You did have the email address. It just says electronic mail address. On page 5, lines 11 through 16, the bill says each person must complete the course of training before he is provided with Internet access to the database. Obviously you mean the site, because there could be multiple people using the same computer to access the database. Do you want each and every one of them to learn how to do it?

Joanee Quirk:
Correct. Right now we have an online system and we generated 165,000 requests last year, mostly practitioners. So the practitioners are very familiar with the program. When I get a new piece of software, they will be required to go through a five- or ten-minute online tutorial on how to use the new system.

Assemblyman Hardy:
Who is "they"?

Joanee Quirk:
The practitioners and anyone else we allow access to. Law enforcement is allowed to get this information, practitioners, and some pharmacies do use our system.

Assemblyman Hardy:
So this would be the practitioners, the pharmacists, the police, and whoever else?

Joanee Quirk:
Yes, anybody that we have registered to use the system.

Assemblyman Hardy:
It is hard to conduct a study without money, as stated in section 9: "conduct a study."

Joanee Quirk:
I have grant money available for studies. I can always apply for another grant and the federal government has just appropriated money to a so-called national database. Many of the states use their existing databases, but they will be given money—depending on how many pharmacies they have registered—for operational costs, and I can use that money for studies.

The federal government has been very active in the prescription monitoring program. Over the years, we have received over $1.5 million for this program. We have done studies and public service. We have an intervention officer that goes out and talks to the patients and gets them into drug rehabilitation. We are about intervention and giving a tool to the practitioners and the dispensers.

Assemblyman Hambrick:
I have first-hand knowledge in the use of this program, and should this legislation pass, I would like this study to go down both sides of the street. Not only patient abuse, but also the physician abuse. I have seen physicians issue thousands of prescriptions. Is that the intent or is it just the patient-abuse side?

Joanee Quirk:
One of the authorized entities is the licensing board and they do use the system. If they have a disciplinary case against a doctor, they will access the system and pull all prescriptions for a certain amount of time.

Assemblyman Hambrick:
Would it then be your intent upon receiving that information to potentially file that with other than an administrative body? Would you go to law enforcement?

Joanee Quirk:
The different licensing boards can certainly join in with law enforcement if it is a criminal activity found in an investigation. We just supply the information about what that prescriber has prescribed to all of their patients. From there it is up to the licensing boards to take disciplinary action. We do not get involved with the State Board of Pharmacy or the Task Force.

Carolyn Cramer, General Counsel, Nevada State Board of Pharmacy:
We are asking that the Task Force be exempted out for federal funds. As you know, they already have the ability to get federal grants. We are asking that they have the ability to spend that money without going through the Purchasing Division.

Assemblyman Hambrick, your point is well taken. That is why we rely on this body to debate where the reports should go. We are trying to get a bill in place that allows pharmacies to have better access to patient information and, hopefully, be able to protect everyone.

Chairwoman Smith:
Are there any questions from the Committee? I see none. I would like to close the hearing on A.B. 326. I know that we have at least two amendments. I would like to see you continue working with folks that are interested in this bill and have amendments. We will bring this bill back again on Wednesday and finish the hearing. We will let you testify, Ms. McMenamin. I know you have an amendment to offer and then you can try to resolve some of the issues in the meantime.

So that we can allow our Committee members to move on, we will go directly to public comment. We have one person here to put a comment on the record and then we will close the meeting.

Rocky Finseth, representing PhRMA, Las Vegas, Nevada:
With me is Clem Cypra, policy counsel with PhRMA. He has flown in from Washington D. C., for the hearing on Assembly Bill 213. I understand that you are going to be rolling that bill. I would like the ability to have Mr. Cypra put some comments on the record.

Chairwoman Smith:
That is fine. I apologize that we do not have the time to hear the bill at this time.

Assembly Bill 213: Requires the establishment of the Cancer Drug Donation Program. (BDR 40-39)

Clemmet Cypra, Policy Counsel, PhRMA, Washington, D.C.:
I am an economist, not a lawyer. I am here because A.B. 213 is a bill called the Cancer Drug Donation Program. I have a problem with the bill. I would have to stand in opposition as it is currently written. When you get a chance to look at the bill, it is section 11 that we have concerns with. It essentially spells out protections from liability for everybody who would be involved in the donation process of a cancer drug, but it does not exempt drug manufacturers.

The real problem, as we see it, is that when drugs are donated or when they leave the factory doors, they are no longer under the control of that manufacturer. The manufacturers are not looking for some abrogation of liability. They are not looking for a break. If ever a pharmaceutical were to be recalled and patient health negatively impacted, as has happened before, a patient who used these drugs would, in fact, have some recourse against the manufacturer.

The issue associated with the drug donation process is that many of these drugs expire in 10 days or 24 days. They require pristine storage conditions. Imagine ten vials of a product stored in a patient's home or in a facility, and those remaining vials could be used again. The problem that exists is that they may not have been stored correctly. Something may have happened and the manufacturers, according to this bill, would be liable for things beyond their control. There are a number of states where we have worked with the trial lawyers and other individuals who want to pass these sorts of programs and we have found compromise.

The compromises we have put forth have been met with resistance. But there are active programs up and running in South Carolina, Florida, and Wyoming. We have found a way to compromise. If these issues arise when you are next hearing this bill, we would be willing to work with any of the concerned parties. We would not like to stand in opposition to the Cancer Society, but as written, the drug manufacturers have serious concerns.

Chairwoman Smith:
We appreciate your testimony and your patience. You have raised issues that will come up when we hear the bill. Is there any comment from the Committee members? I see none.

The meeting is adjourned [at 4:10 p.m.].

RESPECTFULLY SUBMITTED:

Chris Kanowitz
Recording Secretary

Patricia Blackburn
Transcribing Secretary

APPROVED BY:

Assemblywoman Debbie Smith, Chair

DATE:

EXHIBITS

Committee Name: Committee on Health and Human Services

Date: March 30, 2009 **Time of Meeting: 1:38 p.m.**

Bill	Exhibit	Witness / Agency	Description
	A		Agenda
	B		Attendance Roster
	C	Alicia Hansen	Nevada Cancer Systems Overview
	D	Christine Wood	Written testimony
	E	Sheila Baez	Outline of testimony
	F	Tom McCoy	Written testimony
	G	Stacey A. Gross	Outline of testimony
	H	Lewis Musgrove	Outline of testimony
	I	Mary Guinan	Timeline of Childhood Leukemia
	J	Mary Guinan	Summary of Findings
	K	Mary Guinan	Final Report
	L	Julie Tholl DeJan	Angel Kiss Foundation Annual Report
	M	Jennifer Bradley	Written testimony
A.B. 269	N	Elisa Maser	Proposed amendment