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

Seventy-Sixth Session
March 14, 2011

The Committee on Health and Human Services was called to order by Chair April Mastroluca at 1:38 p.m. on Monday, March 14, 2011, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4406 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/76th2011/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 April Mastroluca, Chair
Assemblywoman Peggy Pierce, Vice Chair
Assemblyman Elliot T. Anderson
Assemblywoman Teresa Benitez-Thompson
Assemblyman Steven Brooks
Assemblyman Richard Carrillo
Assemblywoman Lucy Flores
Assemblyman Jason Frierson
Assemblyman Pete Goicoechea
Assemblyman John Hambrick
Assemblyman Scott Hammond
Assemblyman Pete Livermore
Assemblyman Mark Sherwood
Assemblywoman Debbie Smith

COMMITTEE MEMBERS ABSENT:

None

GUEST LEGISLATORS PRESENT:

None

STAFF MEMBERS PRESENT:

Kirsten Coulombe, Committee Policy Analyst
Risa Lang, Committee Counsel
Linda Whimple, Committee Secretary
Olivia Lloyd, Committee Assistant

OTHERS PRESENT:

Luana J. Ritch, Ph.D., Chief, Bureau of Health Statistics, Planning, Epidemiology, and Response, Health Division, Department of Health and Human Services
Paulo S. Pinheiro, M.D., Ph.D., Assistant Professor, Epidemiology, Department of Environmental and Occupational Health, School of Community Health Sciences, University of Nevada, Las Vegas
Debbie Strickland, Executive Director, Northern Nevada Children's Cancer Foundation
Leslie Katich, Programs and Services, Northern Nevada Children's Cancer Foundation
Cheryl Martin, M.S.N., A.R.N.P., O.C.N., Chief Operating Officer and Chief Nursing Executive, Nevada Cancer Institute

Chair Mastroluca:
[Roll was called.] Today we are going to have a presentation and an overview of a few different topics in the area of cancer, including an overview of the Nevada Central Cancer Registry (NCCR), an overview of childhood cancer in Nevada, a presentation from the Northern Nevada Children's Cancer Foundation (NNCCF), and a presentation from the Nevada Cancer Institute (NVCI). We are going to start with Luana Ritch from the Health Division.

Luana J. Ritch, Ph.D., Chief, Bureau of Health Statistics, Planning, Epidemiology, and Response, Health Division, Department of Health and Human Services:
I am the Chief of the Bureau that has the Nevada Central Cancer Registry as one of its programs. I believe that we have our presentation uploaded on Nevada Electronic Legislative Information System (NELIS) (Exhibit C). We have some handouts as well.

The Nevada Central Cancer Registry is a state-based registry that collects cancer data as it is abstracted from medical records at diagnosing facilities, and includes the first course of treatment for each particular case. It is population-based. It is an effort that is useful in retrospective looks at cancer incidence in Nevada. Nevada's Central Cancer Registry meets our national recording requirement within 24 months of the year of diagnosis. The registries do not track incidence as diagnosis occurs. In other words, it is not a real-time registry; the data comes and the complete data is submitted at some point after, usually two years. So our data that we have just submitted in December and January to both the national program of cancer registries at the Centers for Disease Control and Prevention (CDC) and the North American Association of Central Cancer Registries (NAACCR) was for the diagnosis year 2008.

A cancer registry is one place where we can collect a lot of information that pertains to an individual case. It can be used by researchers, epidemiologists, and others to complete the whole story of cancer. The better your data in the registry and the easier it is to access, the more value that data will have for researchers and others who are trying to address cancer in a comprehensive way. The Nevada Central Cancer Registry provides the identified data to researchers and the national programs. The data is collected by abstracting from the medical records of individuals who are diagnosed with cancer. That can be either done by the facility itself—some of our hospitals do that abstraction themselves—or it can be done by an abstractor that the Cancer Registry sends to abstract those cases. We also collect and share data with surrounding states and other states that have Nevada cases and vice versa. We strive to achieve the highest quality data we can. Occasionally we have an incident—and this occurred in 2007—where, for a variety of reasons, including staff vacancies, we may not get all of our cases submitted in time to completely meet what is called the "gold standard." Currently Nevada's Central Cancer Registry has met the Gold Standard for Registry Certification by the North American Association of Central Cancer Registries for seven of the past eight years.

We link with other programs. We link with the state Office of Vital Records, hospital discharge data, Women's Health Connection, and also a health service database in order to increase the number of cases that we are capturing in Nevada, so that we can have a data set as complete as possible that includes all of the cancer cases in Nevada.

I am not going to talk a lot about data. I know that Dr. Pinheiro follows me and will be presenting on some of his research. We do collaborate. The data is useful in many, many programs. It is used for grant applications, planning

services, monitoring health, and retrospective studies to identify or attempt to identify cancer anomalies that may be occurring in the state. That data has increased each year in the number of cases and in the quality and completeness of the data. We currently have reported 12,321 cases for the 2008 case data.

The next two slides are just incidence data for Nevada by gender and race/ethnicity, and then the top five cancers in Nevada. The top five cancers overall—and this is for all individuals of all ages—are prostate cancer, lung and bronchus cancer, invasive breast cancer, colorectal cancer, and urinary bladder cancer. Then there is an "all other" category, which is the 44 percent that makes up all of the other cancer sites that are collected.

I also have a slide that is titled, "Age-Adjusted Cancer Incidence Rates by County of Residence in Nevada." It is preliminary data for 2004 through 2008. The reason I am presenting this is because you will see some problems that we have with Nevada data in that we are dealing with very small numbers in very small populations in many cases, so you can get incidence rates that may swing wildly. They may look extreme on the surface, but when you dig into the data, you realize that a county that maybe had four cases previously now has seven cases diagnosed in this particular year, and next year they may go back down to four cases or less. That can give you some very wide ranges. That is why we cannot look at any one given year for cancer data. We often have to look at multiple years to be able to have any predictability with that data. Cancer registry data is not useful in identifying a cluster, but it is useful when it comes to investigating a cluster, or looking back retrospectively, and the reason for that again is the delay. It is a two-year cycle. We will not have cancers that are diagnosed in this year entered and reported until 2013.

You can access Nevada's cancer data through various national sources, but you can also access Nevada's specific cancer data through the United States Cancer Statistics, NAACCR, and also various other sites within the CDC that provide it. [See page 14 of Exhibit C.]

Regarding our future plans and opportunities for improving the cancer registry, we are looking at linking our data with the National Death Index to get a much better completeness of our data. We are looking at web-enabled reporting for facilities so that we do not have to send abstractors into a hospital. The hospitals can use an online application and send us the data electronically. That will speed up, and hopefully also improve, the quality of the data. We are looking at geocoding of the data so that it will be of much greater use in research efforts, as well as for program planning of services. We are in the process of attempting to build infrastructure in the data for our information

technology structure, our data analysis, and data quality control. Those goals are reflected in our budget request, which will be heard this week.

We are focused on further data analysis and trying to increase the availability of analyzed data, and also making data available to researchers who wish to analyze our Nevada data. There are many possibilities of what we can do to improve Nevada's cancer reporting and the quality of our data. I think our eyes are just now starting to open to the full impact that we can make with the cancer registry data, and that is, in part, due to our collaboration with the University of Nevada, Las Vegas (UNLV), and the researchers there. I would be happy to answer any questions you may have.

Chair Mastroluca:
I recognize what you said about the cancer cluster because of the lag time, but have you seen growth in any types of cancer in Nevada between 2004 and 2008? Are there things that you are concerned about?

Luana Ritch:
Among the childhood cancers, I have not, although I think Dr. Pinheiro might be better suited to answer that question. I was involved with the cancer cluster investigation in Churchill County, and I am very familiar with that particular cluster. I do not believe that our data is showing us anything that is of concern currently among childhood cancer. In adults, particularly in women, we are seeing some alarming cancer rates, especially lung cancer, and there are also some other cancers that we see in the Nevada population that are concerning. We are just now beginning to look at survivability rates and those types of indicators that could tell us more about what is happening with cancer and cancer treatment in Nevada. I think Dr. Pinheiro has some information on that for you.

Chair Mastroluca:
Are all medical professionals required to report to the registry, or is it oncologists? How do you get the information?

Luana Ritch:
The statute requires that any physician or health care facility that diagnoses cancer must report. We also have laboratory reporting. So we get cases from laboratories, pathology laboratories, oncologists, dermatologists, and others that are diagnosing skin cancers. We get them from outpatient facilities as well as inpatient facilities. We also get our case reporting data for Nevada residents who are diagnosed and treated in another state. That data will also be recorded by us. The statute is very broad in terms of who must report. It is not just oncologists. That is part of our work at the Nevada Central Cancer Registry.

In order to be sure we are capturing as many cases as we can, we do outreach to various places, such as imaging centers and various other places, to maximize the reporting of those cases.

Assemblywoman Pierce:
Are you getting names with these to make sure that you are not counting the same person twice?

Luana Ritch:
Yes. We do get identifiers. We get names and other identifiers that help us to deduplicate the registry. It often helps us when we can match up reports that come from a variety of sources. Sometimes that helps us add more data to the file, so we are getting a complete picture on that case, and we do our very best in our data cleaning to eliminate duplications.

Assemblyman Hammond:
You have piqued my curiosity. If I go to an oncologist in California, they are able to report back that data? How so? Is it something that they do voluntarily? Is it something that you as the patient will ask them to do? I am curious how we can get data from outside the state into our registry.

Luana Ritch:
The cancer registries collaborate in each state across the country and we collaborate with the NAACCR and the CDC. States like California have laws similar to those in Nevada. They require the reporting of cancer to a central cancer registry. So our data from out of state will come in a data exchange from that California Cancer Registry to our registry. The data is kept confidential. It is some of the most protected data that we have in public health, and it goes from registry to registry. If you were diagnosed in California and treated in California, that provider is required to report that information to the California registry, and the California registry has a data exchange agreement with Nevada. That is how we get the data.

Assemblywoman Pierce:
How do you track the survival information?

Luana Ritch:
We capture the data and it stays in our database. It does not just stand alone. Every year we take our data from the past and we do what is called "the death clearance process." We match it against death certificates. In the future, we will be matching against the National Death Index to identify individuals in our registry who have died. That data is what is used by the epidemiologists in

determining survivability. Again, Dr. Pinheiro can probably give you a better explanation.

Assemblywoman Pierce:
I have had cancer twice. So the second time I go in the registry, is something going to connect me to the first time?

Luana Ritch:
Yes. If you get diagnosed a second time and it is a new cancer, it is going to go into the registry as a separate case. If it is a recurrence of the original cancer, then it is linked with that original file. The cases would be linked, because it is not uncommon to have individuals diagnosed with more than one cancer over their lifetime.

Assemblywoman Pierce:
Okay. You can put me down as surviving.

Assemblyman Hambrick:
I understand and appreciate hearing about the cluster. Going further down the road, do you also report trending? How does that get back to the general public or to the physicians and their subspecialties? I think trending analysis would be very useful coming out of the registry.

Luana Ritch:
Yes. We do provide the data for trending and we do some internal in-house data trending and we produce that in a cancer report; however, to improve the quality of that report, in the last couple of years we have partnered with UNLV with Dr. Pinheiro, and that is something that he is looking at for our upcoming cancer report. Because of the nature of the data we are dealing with in Nevada, with small numbers and a small population, we often have to wait several years to have enough data to tell us what the trend is and give us a reliable trend. But yes, that is made available and those reports are public. We share them with the Nevada Cancer Coalition, and we share them with any of the cancer entities that are involved in looking at those types of trends. We also look at where they are occurring. We look for the anomalies. We do not necessarily wait for them to be reported to us. We look for anomalies, although it is often that the anomalies are brought to our attention by physicians that are in practice rather than looking retrospectively back.

Paulo S. Pinheiro, M.D., Ph.D., Assistant Professor, Epidemiology, Department of Environmental and Occupational Health, School of Community Health Sciences, University of Nevada, Las Vegas:

My presentation (Exhibit D) is going to be a good complement to what my colleague, Dr. Ritch, has just presented. I will be speaking about cancer in Nevada. I will start with childhood cancer, and then I will refer to the highlights from analysis of data available from the Nevada Central Cancer Registry.

On the first page, the first thing I would like to say is that because childhood cancer is fortunately such a rare event, it is very difficult to actually study the numbers over time. Because the numbers are very small, statistical and epidemiological rules do not apply, so it is difficult to treat this data. On the next slide, we can see that for childhood cancer, Nevada has perfectly average rates compared to the other states in the United States. We have an average of 82 new cancer cases per year. This is for childhood cancers, so we are talking about children younger than 15 years of age. The three main types are leukemia, brain cancer, and lymphoma. You can see that we have 27 new cases of leukemia every year, 14 new brain cancers, and 11 new lymphomas. Within each of these divisions, we have further divisions and more specific diseases. For instance, there is lymphatic leukemia, myeloid leukemia—there are several different types of leukemia that have different risk factors. So it gets very, very difficult to actually study these numbers in a small state like Nevada.

We have approximately ten deaths per year from childhood cancer in Nevada. Now you can see that both the incidence and mortality rates in Nevada are very similar to those of the major states in the U.S.: Texas, California, and New York.

The next slide shows the mortality rates for childhood cancer for Nevada and the United States. You can see a trend. The spiked line is Nevada whereas the straight line is the United States. We can actually see that Nevada rates are just slightly below the U.S. average.

The next slide is about the Fallon cancer cluster that we had in 2000. We did an analysis on Churchill County in terms of the cancer cluster. The definition of a cluster is an unexpected number of cancers within an age group, within a geographical area, and within a definite period of time. Churchill County has a childhood population of around 6,000 children. Based on statistics, we would expect to open three cases every year. This would more or less equate to one case every three years. Or, as you can see in the graph, we had one case diagnosed in 1999, we had seven cases diagnosed in 2000, and then in 2004, we actually had two cases diagnosed. Now if you spread them over six years,

statistically it does not qualify as a cluster. When we do surveillance on a specific county and on leukemias, we do not find evidence of the persistence of the cancer cluster that was detected around 2000.

Finally, in terms of childhood cancer, one issue that is important is that childhood cancer survivors are actually at increased risk for many serious situations, such as these: a second cancer, cognitive impairment, slowed growth, impaired fertility, heart disease, and emotional issues. So it is very, very important to actually follow this cohort of childhood cancer survivors, be it through their general practitioners or through a broader system. By our calculations, there are currently over 700 childhood cancer survivors in Nevada. So this population is very important in terms of surveillance.

The next slides deal with cancer in adults. The main conclusion is that cancer risk patterns in Nevada tend to be average in men, but they do tend to be above average in women, and this may cause some concern. The following slide—slide 8 on page 4 (Exhibit D)—shows, for all cancers, mortality rankings for the last four years for which we have comparative data with the remaining states, and basically Nevada is surrounded by states with low cancer rates. Unfortunately, Nevada does not equal those rates. In men, we are average; we are state No. 35. We can see that, in women, we are No. 10 for mortality. Compare that to Utah, which is No. 51, California (No. 45), and Arizona (No. 49). So there seems to be a pattern of increased cancer risk in Nevada compared to the other states surrounding us. Each cancer is a different story. Each gender is a different story.

I selected the No. 1 problem that could have potential for prevention in Nevada, and that is lung cancer among women. If we had the same rates as the rest of the United States, we would be able to avoid 200 new cases of lung cancer every year, and 112 deaths. Now 100 is a number that does not sound like a lot, but epidemiologically, this is quite remarkable and something that we should be aware of and see if we can do something about. Another problem is going to be colorectal cancer in women. As we are going to see later in this presentation, women present higher rates of cancer.

When it comes to cancer screening, we find that we have very low rates of cancer screening in Nevada compared to the U.S. average. We can see that trend for mammograms for women over 50 years of age, Pap smears for cervical cancer, and colorectal cancer screening. Surprisingly we have a very low colorectal cancer screening rate among women compared to men, and that translates to the increased rates for colorectal cancer in women.

The next slide shows Nevada's ranking for incidence and mortality of certain cancers in non-Hispanic, white women [page 6 of Exhibit D]. We can see in this table that the numbers are actually very marked in the sense that in the incidence rank we are not faring so badly, but when it comes to mortality, we can see that white women in Nevada are No. 3 in terms of the 51 states in the United States. We are No. 8 in terms of breast cancer, No. 2 in terms of lung cancer, No. 1 in colorectal cancer, and No. 1 in cervical cancer. So these numbers really are not a favorable reading of the state of cancer, at least in non-Hispanic, white women in Nevada.

Finally, the last piece of analysis that we did, which we thought would be interesting to share with you, is the question, "Where is the best cancer care in Nevada?" I have been in Nevada for only 1 1/2 years. I asked several other experts this question, and many people would say off the record that the best thing to do is actually get on a plane and go elsewhere. So I thought this would be a good question to study using the cancer registry data, and the cancer registry data has many useful aspects. One question we could ask is, is the best cancer care actually outside of Nevada? Is this a perceived perception or a real perception? So in terms of the real perception, we compared survival rates between Nevada and the United States, but we did not just compare everybody together, because it depends so much on stage of diagnosis. If the quality of care that we have in Nevada is the same as in the rest of the United States, we would equal the survival rates according to stage. What we can see, however, for breast cancer and colorectal cancer, is that survival rates for residents of Nevada are actually below the survival rates of the United States. These differences are significant for both cancers.

The other question is, how many people seek cancer care outside of Nevada? We can see, on slide 14, the percentages for different geographical areas of Nevada. The total is 16 percent. Now there are rare cancers, of course, and we could expect a proportion of people with rare cancers to go outside the state. That is the case for children, for instance, where they need larger hospitals with more experience and more expertise, but for adults, the 16 percent number is definitely increased. If we look at the data by geographic area, Elko, for example, shows about 57 percent seeking care outside of Nevada. There is a proximity to Utah, so that might contribute, but then we see 17 percent for Clark County and 8 percent for northern Nevada. Within Clark County, we can see that zip codes with the highest household income have as many as 1 in 5 patients seeking cancer care outside of the state, whereas in downtown central Las Vegas, the number is closer to 10 percent. Overall, the percentage of people who go outside the state for cancer care is much smaller in northern Nevada than southern Nevada.

The impact of the out-of-state care on Nevadans can be reflected in many issues. One of them is the well-being and survival rates of Nevadans. If people have to drive or change homes, that translates into well-being. Then there is the financial impact—not only on the Nevada health care providers and on the Nevada private insurance companies—but also on the Nevada Medicare and Medicaid programs, because if the price of cancer care is more expensive outside the state, there is going to be a financial impact.

Slide 16 lists some priorities for Nevada in terms of control of cancer. We should try to increase cancer screening rates in the state. Colorectal cancer screening is starting to go on in Nevada, but we need to focus on improving screening rates for breast and cervical cancer, and also guaranteeing that these people are not just going to get screened, but they are actually going to get the treatment that they will need.

Another priority is the surveillance of lung cancer, especially in women. In women, lung cancer is not as connected to cigarette smoking as in men. When we compare data to other states with very high lung cancer rates in women, we see that women in Nevada actually do not smoke as much as women in places like West Virginia or Kentucky, where the lung cancer rates among women are equally high. So one of the possibilities is an occupational exposure in terms of second-hand smoke, or a level of exposure that could in some way affect this pattern of high lung cancer rates in women in the state. But that is research for the future.

Finally, my message is that when putting together this data and important evidence for cancer care in Nevada, it all comes down to the quality of data that is collected by the Nevada Central Cancer Registry, as Dr. Ritch said before. It is important that they have the means for that, because the quality of the data is basic here, to assess quality of care, and also to assess cancer occurrence among Nevadans. Thank you.

Chair Mastroluca:
Thank you very much. There was a lot of information, but it is a lot of good information to have.

Looking at the incidence and mortality rate of women, can you say one way or the other if the relationship between the high mortality rate in certain areas comes from lack of education, lack of access, or finding it too late?

Paulo Pinheiro:
It is possibly a combination of all of those. The main problems here will be lung and colorectal cancer. These cancers are related to lifestyle. We cannot

change the characteristics of our population, and as you know, 25 percent of the population has moved into the state in the last decade. We cannot choose what kind of population we attract. So my point here is that we have to deal with whatever prevalence of lifestyle issues we have. There is nothing that we can pinpoint, but it is probably a combination of all aspects: educational level, social level, and economic level.

Assemblyman Brooks:
Thank you, Doctor, for that enlightening presentation. If it is a lifestyle issue, why is it that we see a higher incidence of colorectal and lung cancer in women than in men?

Paulo Pinheiro:
That is a very good question. In fact, when we speak about cancer, not everyone is equally susceptible to cancer, and that is what we see, for instance, in lung cancer. The pool of susceptible people can be affected more easily in places of high prevalence. We find in Nevada that women have such a different prevalence of risk factors compared to women in other states, and that translates into this immunological pattern, whereas men tend to smoke more than women everywhere. When you put this in comparison in Nevada, women and men are pretty much at the same place in terms of prevalence, and that increases the rates in terms of women, just as an example.

Assemblyman Brooks:
So, in fact, they are the same. It is just that the females are higher in Nevada than they would be in other states, but they are equivalent to males.

Paulo Pinheiro:
Yes, in terms of prevalence of risk factors. Now there is a potential for prevention. If you compare it to what women do in other states, then we can see that there is a potential for prevention if we target female populations; or if we can do something in terms of public health programs for women, then we could improve that situation given the data from the other states as well, in a comparative perspective.

Assemblyman Hambrick:
Doctor, I would like to refer back to slide No. 5. Many times when we hear testimony, we tend to deal in abstracts, and many times there are numbers and real people behind these abstracts. We have had now almost a generation to look at what happened in Churchill County. Has there been a definitive decision or explanation as to what caused this? I know you do not want to use the term "anomaly," because statistically you have to be careful. But for us lay people, that seemed to be a real blip on the radar screen at one time, particularly if you

lived in Churchill County. Have we ever been able to determine what caused that blip?

Paulo Pinheiro:
The answer is no. That is very difficult in terms of cancer clusters. We do profound analysis, we do a lot of research studies on it, and many times, more often than not, we actually do not find a cause for the actual cancer cluster. Now this cancer cluster of leukemia cases in Churchill County was possibly one of the best studies in the world. We had collaboration from everywhere, and Dr. Ritch knows more about that than anyone else. We found some increased levels of arsenic and tungsten in the drinking water, but that has never been established as a causative link to the actual cancer cluster among children. So the answer to your question is no.

Assemblyman Hambrick:
Not all questions have good answers. Thank you.

Assemblywoman Pierce:
Can you go back to slide 8 (Exhibit D), because I do not quite understand it. Do the rankings indicate least survivability or most survivability?

Paulo Pinheiro:
It actually means mortality. Mortality is a complex indicator because mortality depends on incidence. If you do not get the cancer, of course, you are never going to die of it. Survival is something different. Survival means how many of the cancer patients are actually going to survive? So they are two different concepts. Mortality is more encompassing. Number 1 would be the one with the highest mortality, and No. 51 would be the one with the lowest mortality. What you see here is that our surrounding states are Nos. 45, 49, and 51, but Nevada is No. 10 in terms of mortality. Now this means that you have an increased incidence of cancer, but we probably also have, as I showed in another slide, low survival. Both of those contribute to the higher mortality.

Assemblywoman Pierce:
What about survival rates on slide 13? Does that have something to do with the low levels of screening for women?

Paulo Pinheiro:
Actually, no, because this is after diagnosis. Once a person is diagnosed, the cancer may have been discovered by population screening, by opportunistic screening by the doctor. This is an analysis by stage, so screening has nothing to do with this. We separate those who were diagnosed at the local stage and

the regional stage, and then we compare our data with those of the other states.

Assemblyman Brooks:
How many of these are secondary-type issues where the primary issue may be another preexisting disease and cancer is brought up as a secondary issue?

Paulo Pinheiro:
These are all primary cancers. In terms of registry data, we have the primary data of the primary cancer and then we record metastasis within the primary cancer. It is only if the second cancer is completely independent from the first that it will count as a second primary, but there are no metastases here in terms of these numbers that I presented.

Assemblyman Brooks:
How many may have been from someone having AIDS or HIV or something like that, and as a result they were more predisposed to get cancer?

Paulo Pinheiro:
We do not link cases with diseases such as HIV, so the answer to that question is impossible to give.

Chair Mastroluca:
Thank you very much for your presentation. We appreciate it.

Debbie Strickland, Executive Director, Northern Nevada Children's Cancer Foundation:
On behalf of Northern Nevada Children's Cancer Foundation and our family, I would like to thank you for inviting us here today to speak about our organization (Exhibit E).

Northern Nevada Children's Cancer Foundation is the only organization dedicated solely to supporting children with cancer and their families in northern Nevada and the eastern Sierra regions. We are a comprehensive resource organization providing financial and emotional assistance. We also provide advocacy, awareness, and research. Since our inception almost ten years ago, we have financially assisted 318 families with over $1.2 million in financial assistance.

Thirteen years ago my eyes were opened. This is when I began to fear that one of my own babies could have cancer. My friend lost her five-year-old son to neuroblastoma. I learned the fearful facts that 1 out of 330 children between birth and 20 years of age are diagnosed with cancer. This is also when

I learned the fact that childhood cancer is the No. 1 disease-related killer of children—more than AIDS, asthma, diabetes, and cystic fibrosis combined. This is when this information sunk in. My life forever changed, and this is why I am here now, speaking in front of this Committee and lending a voice for those that are in the fight.

Northern Nevada Children's Cancer Foundation has helped 84 families in the last year. All initially left the area to seek their own treatment. In contrast to the registry information, the majority of the children that we see—in fact, all of them last year—leave the area to receive treatment, particularly in northern Nevada. This is because treating adult cancer is completely different than treating pediatric cancer. At this time, our local children with cancer are best served by traveling to a full-scale children's hospital to begin their treatment. Down the road, hopefully our children will have the opportunity to come back to our local hospitals and receive some of their treatment, but right now the protocols and their treatments are being done outside our area.

Of the 174 children we have serviced, the average treatment plan is between one and three years. Many of these children will have secondary treatments. Northern Nevada Children's Cancer Foundation will also help to assist during this stage as well, but the majority of our funding is focused on the first one to three years.

Northern Nevada Children's Cancer Foundation serves families with children under the age of 19 in treatment for cancer and in follow-up care for cancer. We service the eastern Sierra region including Lake Tahoe, Truckee, Quincy, and Susanville, California. Our southern border is Tonopah, Nevada.

We are seeing an increase in the number of families. We believe that this is due to the overall fact that cancer is increasing. We also believe that it is because these families are becoming more aware of Northern Nevada Children's Cancer Foundation, so more are walking through our door. We also believe that it is due to the downturn. A lot of these families that could normally handle this type of situation are having to turn to us for financial assistance. We use our monies to help families that leave the area with household expenses. We pay mortgages, rent, utilities, travel expenses, lodging, food in the cafeteria, and tolls. We also use our monies to help them with medical and pharmaceutical copayments. We provide care packages when our children and families leave our area. We want them to know our community cares. These care packages have stuffed animals and blankets that can fit their beds. So it sends the message to our families that as a community we support them.

We have support groups and clinic assistance, and we provide resource guides. We also have events for children such as Kids' Club and Reel Kids, Real Living so they can come together as a group and support one another. We provide an Adopt-A-Family program and we have a holiday program. Part of our mission, we believe, is advocacy, awareness, and research. In fact, this week a representative from NNCCF will go to Washington and speak to our legislators about appropriating and having funds available to serve some of these families.

In addition, we sponsor awareness events. We set aside September 10 as "Northern Nevada Unites in the Fight Against Cancer" Awareness Day and we will be picking a park. We ask for a lot of our collaborative partners to come together. Families and their caregivers, medical professionals, and community organizations come together, and we have one voice for childhood cancer. We have an awareness campaign and this year alone we will distribute 5,000 gold ribbons, which is the national symbol for childhood cancer. We will also distribute cancer facts.

Another awareness and fundraising event is the St. Baldrick's event, which is actually scheduled for this Thursday. I extend an invitation to all of you to please come out on Thursday to the Exhibit Hall at the Reno-Sparks Livestock Events Center. You will see close to 300 participants. They go out and get donations to shave their heads, they come through, and they get their heads shaved. There will be about 1,000 spectators who will afford us a forum in which we can also convey our message and the facts about childhood cancers. So if you are interested in attending, please let me know, and I will reserve a special spot for you so you can observe and watch this very, very moving event. We hope to raise about $120,000, which will go directly to the Children's Oncology Group to help find a cure.

In conclusion, you sit in a unique position as part of this Committee. I beg of you not to be like me and wait until someone close to you actually has a child with cancer, but to open your eyes now and see that it does exist and is a prevalent problem in northern Nevada. I ask you to leave today with your eyes open and a willingness to make a difference to families like Leslie Katich's, who sits with me today. Northern Nevada Children's Cancer Foundation has the honor of having Leslie work with our families, distribute funds, and provide that emotional support that they need when they come in. I have asked her to join us today to briefly speak to you as a mom who has lived the journey and actually has had a child in treatment.

Leslie Katich, Programs and Services, Northern Nevada Children's Cancer Foundation:

Along with the customary fanfare that goes along with the typical overachieving teenager, my daughter, Kristin, had been experiencing bouts of breathlessness. She was an athlete, an avid runner, and a cheerleader at a local high school. She was passing out at her events, and this was very alarming. She also began sleeping a lot. One particular day in December she was feeling a little bit better, but on this day, because she had been nominated as the winter princess at her high school, her friends came over and they were going to rehearse for an assembly at the high school the next day. They were in the living room all night laughing and dancing away. Within a few short hours, she came crawling into our bedroom on her hands and knees, and through her sobs and tears told us she had excruciating pain in her knees.

We went to the doctor as soon as we could that morning, and he did some laboratory work, and that led us to another doctor—who happened to be in town—who was a pediatric hematologist/oncologist. It was there that we learned that Kristin had acute lymphoblastic leukemia (ALL). We were also informed that she would be receiving the bulk of her intensive treatment out of state in Oakland, California. We asked the doctor when that would begin, and the doctor replied, "Today." We were stunned, and our thoughts, of course, were for our daughter, but also for the three other children that we had at home—her three brothers. Fortunately we had good friends who immediately took them into their homes during a very busy holiday season. We left half-decorated gingerbread houses and Christmas cookies for neighbors on the kitchen counter, and our delightful, anticipated Christmas gifts were left unattended. We shut the door and headed for Oakland that day. It took us 5 1/2 hours to get there because of the weather; it should have only taken us about 3 1/2 hours.

Once we settled into our new home in Oakland, I was grateful still to have my daughter beside me and to have the help that she needed to get better, but I also realized it was the dawning of a completely new life for our family, and that the life that we knew was gone, and it was just gone forever. It was in Oakland that we learned the real statistics for her particular ALL. The doctors gave her a 20 percent chance of survival her first year, and we were stunned. This was the one piece of information we did not share with her because of her age. At 17, she clearly understood what she was facing and the language and everything that the doctors were presenting to us. But that piece of information we did not want to divulge to her, and I know you can understand why we would not do that.

To be honest with you, I do not know how many times we made the 450-mile round trip to Oakland for the next 1 1/2 years. I cannot count or tell you how many transfusions she had. We became experts at being admitted to the hospital, and I have lost track of those, because the reality was that it did not change a thing. She needed to be where she could get the treatment to save her life, and that was at that treating hospital at that time. The number of trips, the price of gasoline, were all uncontrolled variables and it did not change the fact that, for part of her journey, that is where we needed to be to save her life. There was no other option for us.

Kristin tried her best to deal with the travel and being away from her support group. I was constantly trying to make the adventure of going down there a little bit easier, to lighten the load, and to soften the reality of the situation. I also tried to make sure that the other children I left at home constantly knew that they still had a mother and did not feel abandoned. Another sad reality was that texting became our new line of communication. It was just another fact that proved to us that we were separated by a great deal of distance and still trying to communicate, but we had no choice in the matter. Kristin often said that she felt alone and it was for a very good reason. She was constantly being taken away for treatment, away from her home, her family, her friends, familiar faces, and familiar places. But after enduring 828 days of grueling chemotherapy, I am proud to say that she has beaten the odds and she is living cancer free today, and it has been just over three years for her.

Please know that the words “cancer free” come at a very, very high price. Ultimately Kristin paid the highest price, but for the three boys that we left at home on that snowy December day in 2007, their lives also were changed forever. My husband took on a dual role as a parent, since I had just dropped the ball completely. He was amazing and took over. He picked up the ball where I had stopped. Along with Kristin’s high-risk leukemia comes a high risk of relapse, and that is a thought that we have to live with every day.

Each of you here today, I know you do not need any further convincing that cancer is a devastating diagnosis. A diagnosis for you or me during our younger years or lifetime, particularly her diagnosis, would most likely have been a death sentence. For many of our northern Nevada families, to find that cure, it must be sought in a neighboring state. This adds an even greater burden than just the diagnosis would bring. It weighs heavy on the load that every family needs to carry. Children with cancer need us to do more, and our northern Nevada families need us to do more, each and every one of us. We all know that more cannot be done without your support. It is as simple as that. I implore you to keep funding and supporting organizations like the Northern Nevada Children’s

Cancer Foundation so that families can get to the treatment that they need and that their children can have the promise of growing old. Thank you.

Chair Mastroluca:
Thank you so much for sharing such a moving story and sharing such a big part of your life with us. We appreciate it and it really shows the honor of the work that your organization does. Thank you for being there. I hope that the community and the state continue to support that as it is definitely a need.

Assemblywoman Smith:
I want to first disclose that I am on the advisory board of the Northern Nevada Children's Cancer Foundation. Last session we heard from the Angel Kiss Foundation and the Keaton Raphael Memorial group, and they merged into this very fine organization. It is so important for me to hear this message to the legislators because most people do not know that our children have to go out of state for treatment. I watched one of my own friends go through it with her child, and that is how I became connected to this group. I saw what they had to go through every week, making the trek over the mountain, rain, shine, or snow, to do what they needed to do, and how families are disrupted and the costs of that on an everyday basis are so extreme. I am very grateful that we have organizations that support our families, both emotionally and monetarily. It really brings home to me that we need to keep working to make sure that whether it is childhood cancer or adult cancer, we have the facilities in our state that we need to treat people who are sick. Having to leave the state complicates it so much more. I think some progress had started in that area before the recession hit, and that has not been able to progress. Hopefully we will be able to keep shining the light on this issue and making sure that decision makers, funders, and people who are talking about medical services in our state are acutely aware that we need to be able to provide this type of service for our own residents in Nevada. Thank you, Madam Chairman, for bringing these presentations. I really appreciate it.

Cheryl Martin, M.S.N., A.R.N.P., O.C.N., Chief Operating Officer and Chief Nursing Executive, Nevada Cancer Institute:
Thank you very much for giving me and the Nevada Cancer Institute (NVCI) the opportunity to speak with you today. In this room we have had many advocates and friends of the Nevada Cancer Institute (NCI), and this Legislature has been incredibly supportive of the Nevada Cancer Institute since our inception about eight years ago, and over the last 5 1/2 years since we have been giving direct patient care. I want you to know that we are all very, very grateful for that.

I am here today to talk to you about how the Nevada Cancer Institute has grown in this time span, and as the official cancer institute of the state, how we are making strides to build Nevada's health care infrastructure and what that means for economic development in Nevada. We are here as a partner and as a resource for you.

If you go to the slide of my presentation (Exhibit F) where it speaks to our mission statement, many of you have worked with us over the years, and you know this statement. For those of you who are new and do not know, I want to briefly touch upon the mission. It is our overarching goal that the NVCI become a National Cancer Institute-designated comprehensive cancer center. What this means for Nevada is that patients can find the best cancer care without leaving the state, as we have just heard today what happens with pediatric cancers. Federal funds will also be drawn regularly to strengthen Nevada's medical research infrastructure.

As you can see from the next slide, we have our core research areas. Biomarkers are those items that can help judge your cancer as you are progressing through your cure; those are all the lab work and rates and things being done. We are working strong on many biomarkers. A great deal of research is happening in the area of genetics because we are thinking that cancer is very individualized and specific. You can see that in our cell research we do a lot of drug and targeted development and discovery as well.

In our treatment area, we definitely have the medical research and hematology. You can see the areas that we cover on the "Treatment" slide. We are up to 30 faculty members now. In the area of radiation oncology, we have—through federal funding—been able to add even more state-of-the-art equipment and expertise to help in the area of radiation. For example, we have a Varian TrueBeam, which is very much incomparable and is somewhat the latest and greatest in comparison with the CyberKnife. We do a great deal of our diagnosis in pathology, as well as working with the state registry very closely for those first diagnostic treatments.

For those of you who have known us, you can see our main campus has grown. We have grown from the flagship facility into two more buildings. The Greenspun Family Pavilion is where our administrative support is located, and where we hope to open some very strong high-risk screening. This was mentioned earlier, that it is an important adventure for us to really be looking at with patients, especially as you look at women with lung cancer. The other new building is our Ralph and Betty Engelstad Cancer Research Building, where we have several of our researchers already housed.

We do outreach statewide. As you can see, we have facilities in the Las Vegas area, we have a Reno office, and we have an Elko office (Exhibit F). We have the Hope Coach and that is our mobile mammography unit, and we have touched a lot of lives throughout the state. The Hope Coach goes for a week at a time to many areas, and we have been fortunate, through some grants, to be able to fund those who are either underinsured or uninsured in those areas. I want to specifically mention that in the Elko area, Newmont Mining Corporation has been extremely generous and is funding a full program that allows for support in that area. It also funds a full nursing navigator for them in that area, and we are very blessed with that.

We have patients who come from multiple areas because we have a lot of renowned doctors who are very specialized in their care, so patients will follow those physicians. You can see that we have treated about 15,000 patients since opening in the summer of 2005. This just demonstrates that part of our goal is to reach beyond Nevada, the Southwest, and across the country.

That is a little bit about what we have been doing. Again, I want to not only thank you for supporting our efforts, but show you how we are trying to leverage support to help build Nevada's health care infrastructure, and how that really helps the future economy. We have been recruiting the best. As you can see, there are very renowned names of cancer centers across the country associated with our physicians. We are all concerned about the brain drain, about talent leaving the state, and it really is not just our patients who leave the state. It is also our medical professionals.

We have been fortunate enough to receive, from the University of Nevada School of Medicine, the first oncology fellowship specialty in the state. We currently have four fellows. They started last July, will complete their first year in July, and have a remaining year. Then we will have five more fellows who will be coming on board. The advantage of that is that we know statistically that if fellows are trained in the state, many will stay in the state. So we are hoping to keep the best. In that relationship, we work very strongly with the Nevada System of Higher Education, and we are really committed to doing what it takes to support the higher education partner that we have.

One of the other things we are doing to build the future is our Plus One Program, and this is one of several of the American Recovery and Reinvestment Act (ARRA) grants that we have received. You can see that one is a very generous grant that supports training, not just fellows and future physicians, but future nurses and other allied health workers as well. This Plus One Program allows us to work in a partnership with Workforce Connections and the College of Southern Nevada. We are taking new graduates in this program. We all

know there is a nursing shortage in this country, yet there are no nursing jobs for these nurses. We are taking new graduates and training them in the specialty of oncology, so this will make them more marketable in other locations and hopefully even for ourselves.

Other ARRA funds, as you can see in the next slide (Exhibit F), were used for the colon cancer screening navigation program in which we are partnered with the University of Nevada, Reno (UNR). We are a subcontractor. We are also a subcontractor with the Smoke Free Life program, and we have received other awards from ARRA that have helped us in buying state-of-the-art equipment.

We do not stop with funding just from those grants; our research faculty receives federal grants and they also work on drug development. This is also an area that helps with the economy and the opportunity to create jobs. As we work with the grants on the research and drug development, this could bring business development to the area as well as technology transfer and patent development, and that also brings new business to the area.

Our clinical faculty members bring a lot of expertise to the state, and we hope that in our art of treatment, drug development, new clinical trials, and everything we have to offer, this brings opportunity for those patients who have previously left the state. We have treated many patients who continue to be able to stay in the state through some of our Phase I programs that we are building as well as other clinical trial opportunities, and you can see the numbers that we have been able to support.

With this Legislature and previous legislative support, we have been able to make strides for building the health care infrastructure and help to move the economy forward. These efforts will continue to grow as we build. That is our plan and our goal as we strengthen our state's higher education system. I probably cannot stress that enough, the importance of us trying to build that in order to keep the more highly educated in the state and support quality and competition for the health care providers in the state. It is very essential.

Today, I want to emphasize that we are here as your resource. I know there are many times things come up and there may be questions, and we want to assure you that we are here to be a resource. I know that sometimes it might be difficult for you to remember who was at the Nevada Cancer Institute and who was that Cheryl Martin sitting there. I know you are all familiar with Bryan Gresh, and he is more than willing to make sure any question that you might have is answered, or he will get any health care question to us directly. Are there any questions?

Chair Mastroluca:
Could you talk about ways that Nevada can specifically work to try and improve our fight with cancer? What can we do as a state?

Cheryl Martin:
I would have to tell you that the advantage has got to be how we look at screening. Patients need to be screened more when they are being reached at the primary care physician area and those programs. I know it is very difficult working with primary care physicians because they do not have a lot of time with a patient. So we should look at ways that we could make sure the screening could be done more easily, and how they could keep it on their forefront as well.

Chair Mastroluca:
That would show one of the reasons behind having the mobile unit that you mentioned—trying to get that screening out into the community to make it a little more accessible?

Cheryl Martin:
Absolutely. We do a great deal of that with working with employers. That is another great way of doing it. We bring the mobile mammography unit to places of employment. As we move outside of the Clark County area, we go to many, many towns, small and large. The people on the mobile mammogram unit will go to the local restaurants and it is amazing. We have had great response from people when they recognize it is there for the day. So we are really helping that population very well.

Assemblyman Hambrick:
Just for your information, former First Lady of Nevada Dema Guinn had the Mammovan. Is this the same program, but utilizing a different organizational group?

Cheryl Martin:
There is the state mammography van that goes around, and there is also the Nevada Cancer Institute Hope Coach. We work very strongly in partnership with the state mammography van, so we make sure that we do not sit right behind each other when we go to places. We make sure we can reach the larger populations. So it is very similar, and our machines are very much the same.

Assemblywoman Smith:
Just an editorial comment—you may be the only one in the state, because the funding for that is set to go away very soon. We appreciate what you do.

I want to ask about grant funds. I know you have been the recipient of some amazing grants, and as someone who sat through the Interim Finance Committee's Subcommittee for Federal Stimulus Oversight, we saw some great grant news come through that committee about your institute. I am wondering how that is looking generally, and if you are seeing growth on the horizon for you, in being able to expand your services outside Las Vegas.

Cheryl Martin:
We have. I would tell you we put grants through very, very frequently. The art of grant writing is that you have to constantly write. We have a team and we have great people who support this team to make sure that we continuously seek grants. We are as concerned as anyone else that from a federal standpoint there is a decrease in grant funding, most definitely from the National Cancer Institute, which is where we hope ultimately to get some grant funding. As opposed to going out and getting more grants for the mobile mammography unit to go beyond Clark County—those have been grants that we have been able to obtain from local organizations or from national organizations that offer money for us to go and do that—it has been much harder to get other funds to move outside Clark County. But that is absolutely our goal, which is why we do much of our grant writing.

Assemblywoman Smith:
Thank you, and congratulations for what you have done so far.

Assemblyman Brooks:
Is there any correlation between you, UNR, and UNLV? Do you have partnerships where there is an expedited Ph.D. program in oncology?

Cheryl Martin:
At this time, no, not to my knowledge. We do work with other areas as we are putting grants together, because—like the Nevada Central Cancer Registry and the School of Medicine—we need their data and their information, which helps us write grants. We have not specifically gone into that type of education level.

Chair Mastroluca:
Thank you very much for your presentation.

Is there anyone here for public comment? [There was no response.] Any comments from the Committee? [There was no response.]

The meeting is adjourned [at 2:51 p.m.].

RESPECTFULLY SUBMITTED:

_____
Linda Whimple
Committee Secretary

APPROVED BY:

_____
Assemblywoman April Mastroluca, Chair

DATE: _____

EXHIBITS

Committee Name: Committee on Health and Human Services

Date: March 14, 2011 Time of Meeting: 1:38 p.m.

Bill	Exhibit	Witness / Agency	Description
	A		Agenda
	B		Attendance Roster
	C	Luana Ritch	Nevada Central Cancer Registry
	D	Paulo Pinheiro	Cancer in Nevada
	E	Debbie Strickland	Northern Nevada Children's Cancer Foundation
	F	Cheryl Martin	Nevada Cancer Institute Slide Presentation