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

# Seventy-Seventh Session March 15, 2013

The Committee on Health and Human Services was called to order by Chair Marilyn Dondero Loop at 12:46 p.m. on Friday, March 15, 2013, in Room 3138 of the Legislative Building, 401 S. Carson St., Carson City, NV. Copies of the minutes, including the Agenda (<a href="Exhibit A">Exhibit A</a>), the Attendance Roster (<a href="Exhibit B">Exhibit B</a>), 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 nelis.leg.state.nv.us/77th2013. 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 Marilyn Dondero Loop, Chair Assemblywoman Ellen B. Spiegel, Vice Chair Assemblywoman Teresa Benitez-Thompson Assemblyman Wesley Duncan Assemblyman Andy Eisen Assemblywoman Michele Fiore Assemblyman John Hambrick Assemblyman Pat Hickey Assemblyman Joseph M. Hogan Assemblyman Andrew Martin Assemblyman James Oscarson Assemblywoman Peggy Pierce Assemblyman Michael Sprinkle

# **COMMITTEE MEMBERS ABSENT:**

Assemblyman Steven Brooks (excused)

#### **GUEST LEGISLATORS PRESENT:**

Assemblyman Richard Carrillo, Clark County Assembly District No. 18



#### **STAFF MEMBERS PRESENT:**

Kirsten Bugenig, Committee Policy Analyst Terry Horgan, Committee Secretary Macy Young, Committee Assistant

#### **OTHERS PRESENT:**

Rachel Bowe, Private Citizen, Las Vegas, Nevada Tracy Copeland, Private Citizen, Reno, Nevada Michelle Middleton, Private Citizen, Carson City, Nevada

#### Chair Dondero Loop:

Before we begin our bill hearing today we have a bill draft request (BDR) introduction for Committee action. Bill Draft Request 73 was requested by the Legislative Committee on Child Welfare and Juvenile Justice. The measure revises various provisions concerning the abuse and neglect of a child. I will entertain a motion to introduce BDR 38-73.

**BDR 38-73**—Revises various provisions concerning the abuse or neglect of a child. (Later introduced as Assembly Bill 315.)

ASSEMBLYMAN EISEN MOVED FOR COMMITTEE INTRODUCTION OF BDR 38-73.

ASSEMBLYMAN OSCARSON SECONDED THE MOTION.

THE MOTION PASSED. (ASSEMBLYMEN BROOKS AND HOGAN WERE ABSENT FOR THE VOTE.)

I will now open the hearing on Assembly Bill 144.

Assembly Bill 144: Revises certain provisions pertaining to anatomical gifts. (BDR 40-141)

#### Assemblyman Richard Carrillo, Clark County Assembly District No. 18:

Current law allows a person to make an anatomical gift at the time of death. This gift can be of the donor's body or part thereof and can be used for medical education, scientific research, or organ transplant if it is designated by a signed document such as a will or driver's license. Additionally, an unemancipated minor may make an anatomical gift if he or she is authorized under state law to apply for a driver's license and is at least 16 years of age. Further, a parent of

a donor who is reasonably available may revoke or amend an anatomical gift of a minor donor's body or parts.

This bill creates an exception such that if a donor who is an unemancipated minor dies, and at the time of his or her death the donor was at least 16 years of age and held a valid driver's license, a parent of a donor is prohibited from revoking or amending the anatomical gift of a minor donor's body or part.

To my right is Rachel Bowe who came to me with the idea for this legislation, so I will pass it on to her.

# Rachel Bowe, Private Citizen, Las Vegas, Nevada:

I first became interested in organ donation about the time I started high school. I was interested in pursuing biotechnology, and at that time there were high schools in Las Vegas where I could study this. I wanted to look into organ donation, tissue procurement, and related sciences. That is how my interest in organ donation was initially sparked. Around the fall of 2011 I started looking into ideas for a Girl Scout Gold Award project. I was still really interested in organ donation and wanted to do something involving that, but did not know exactly what. I was talking to some women from the Gold Alliance Committee at the Las Vegas Girl Scout Council and they brought to my attention that, while a minor could express a wish to be an organ donor, that wish was not regarded as law. It was more of a wish, but the status could be revoked by a parent or guardian. That caught my attention because, at the time I signed paperwork to get my driver's license at age 16, I had also expressed that I wanted to be an organ donor. I thought that was regarded as law and that the status was final. That was my decision, my choice; then I found out that it was not.

I started working on my Gold Award project in two parts. I was working on raising awareness for organ donation in southern Nevada, and I was also working with Assemblyman Richard Carrillo to bring this change into law. Raising awareness in southern Nevada took the form of passing out pamphlets in Las Vegas, which was quite difficult as a Girl Scout by myself. I was not affiliated with any of the major organizations even though I had worked with them to secure information and create my pamphlet.

Working with Assemblyman Carrillo has meant being in contact for over a year to make this happen. I am here today because I believe that at 16 a minor is competent enough to express the wish to be an organ donor and to have that wish regarded as law. They should be able to enter that legal contract stating what they wish to do with their body if they should die between the ages of 16 and 18. The decision should not default to their parents or guardians.

Since we assume minors will drive safely and legally on our roads, we already trust them to have a certain level of competency, so they should be able to make this decision. We trust that they have learned to drive safely, gone through driver's education, and read the handbooks. There is information about donation throughout those sources of information, so it is not as though they would be coming into this contract blindly. They have already heard about organ donation and most likely talked to people about it before signing the paperwork saying they wish to be donors. I know I talked to people about it before I signed. When this wish is expressed, it should be treated as law. Since we trust them to drive legally, we should also trust them to make an informed decision about what they want to do with their organs if they were to die before the age of 18.

# **Chair Dondero Loop:**

Congratulations on working on this project. I believe there are some fellow Girl Scouts on this panel. Would you like to go ahead and show us your presentation?

[Ms. Bowe showed a video in which several young people, with driver's licenses but less than 18 years of age, and one paramedic with a seven-year-old child, expressed their support for this legislation.]

Are there any additional comments or questions from the Committee?

#### **Assemblyman Oscarson:**

I have worked in emergency rooms where decisions concerning organ harvest had to be made by parents. Allowing an adolescent younger than 18 to make that decision and having it on record makes it much easier for a parent to make that decision. It is no different than an advance directive. I believe this is important and I applaud your efforts. From a parent's point of view, it would make it a lot easier for me if I knew that was what my child wanted to do and had designated it to be done.

# Assemblyman Eisen:

Ms. Bowe, you obviously spent a lot of work on this project and spent a lot of time to understand the issue and bring this bill before us. The question I have is one of scope. You have made a strong case for the permanency of a decision by an adolescent between the ages of 16 and 18 with regard to their wishes to be an organ donor. Why is this tied specifically to having a driver's license? What would happen to a 17-year-old who does not have a driver's license but has an identification (ID) card, which is another mechanism through which a donation could be made. Why would that not also be irrevocable at the time of

their death? Is there a particular reason you chose driver's licenses, or was it a matter of simplicity?

#### Rachel Bowe:

It was more a matter of simplicity, but there really is no reason why it should not extend to a 17-year-old with an identification card. I understand your point. There really is no reason it should not extend that far.

# **Assemblyman Hambrick:**

Have you ever heard the term "DNR"—do not resuscitate? If this bill would pass, do you think a 16- or 17-year-old should also be able to sign a document that they do not wish to be resuscitated? Do you think that decision should be up to them or up to their parents? We are on a slippery slope; how far would you want to go with this?

#### Rachel Bowe:

For now I am more concerned about just dealing with organ donation, since this is specifically tied to an expressed wish on a driver's license or identification card. The pathway for this has already been set up. The do-not-resuscitate directive has not been set up; there is no specific pathway that I know of for a minor to do that. What I am trying to do is solidify a minor's decision to donate his or her organs if he or she were to die before becoming a legal adult.

#### **Assemblywoman Pierce:**

I am the only person here today who was on this Committee in 2007. In 2007 this Committee passed a bill, Senate Bill No. 169 of the 74th Session. It was a uniform law on anatomical gifts. I was the only person in this building who voted against it because I thought there was a lot wrong with it, and this was one of the things that was wrong with it. I support this bill; it is a very small step toward fixing what I think we did wrong in 2007. It would be interesting to know if what we did in 2007 actually increased the number of anatomical donations.

# **Assemblyman Sprinkle:**

Having worked in emergency medicine as a paramedic for the last 20 years, I am extremely supportive of organ donation and the impact it can have on so many other people's lives. From that aspect, I am very supportive of what you are doing. I must say that I am a little concerned, and I believe this is where Assemblyman Hambrick was going as well. We set that 18-year-old age limit because we are talking about legal contracts. We are talking about a parent's right to look out for the best interests of their children. While I understand what you are trying to do, I also am concerned about the precedent that this will set

for other things related to 16- and 17-year olds. I have two 18-year-old boys and one 15-year-old and I know they would love to be able to make their own decisions all the time. I am on the fence about this. I do not know if there is a way to work around that. Maybe there could be a mutual document both the teenagers and their parents could sign that would be irrevocable once signed. The parents would still be part of it. I do believe parents have the right to look out for what they feel are the best interests of their children, even if that child has already passed away.

# Assemblyman Hickey:

You have done a fine job arguing for this bill, and there have been some compelling questions posed. In researching this bill, did you interview parents? What were the concerns you came across from families who might appreciate organ donations, but might have reservations for religious, personal, or other reasons? Did you encounter that and how do you feel this bill takes into account the family concerns that have been raised?

#### Rachel Bowe:

As far as religious concerns, one of my supporters here with me today told me there are only two religions that do not necessarily support organ donations. One is Gypsies and the other religion is not a very common one; so from a religious aspect, that is not too big a concern.

As far as parental concerns go, organ donation is generally something that a parent and a child will discuss at some point. When a child applies for a driver's license, a parent has to go with that child to sign certain documents. A 16-year-old cannot just walk into the Department of Motor Vehicles (DMV) to apply for a license. A parent is involved throughout this whole process, so at some point there is discussion between the child and the parent about these wishes. Also, if the child could express this wish and have that decision respected by law, it reduces the stress on the parent in the event that the child does die. That decision is no longer put on the parent to deal with. At some point, the parent and child would have discussed it.

# **Assemblyman Hickey:**

I am close to what Assemblyman Sprinkle is suggesting. If there were joint participation, would you be amenable to that? Certainly a child who is going to make that decision probably has discussed it with either a parent or a guardian. Would you be open to that? Just as your example with the driver's licenses and many other contracts and licenses—you have to get parents' permission at some points. Would you be open to adding that?

#### Rachel Bowe:

I would be totally open to that. That is a great idea and also encourages more discussion between the parent and child. That is not something I necessarily thought of prior to this. I am glad that Assemblyman Sprinkle and Assemblyman Hickey brought it up because it is a great idea. It encourages more discussion within the family and will ultimately bring families closer in that respect.

# **Assemblyman Martin:**

You made a wonderful presentation and should be congratulated. You are so well-spoken, and it is greatly appreciated.

Obviously, we are battling an issue of age of consent, contract age, minority, individual liberty, and need. During your research, have you determined what is really going on out there? Let us say there is an accident and the 16- or 17-year-old has indicated that they wish to donate organs and suddenly the parents say no. Does that happen very often? I am trying to get a feel for the scope of the issue.

#### Rachel Bowe:

I tried to find that statistic for this presentation, but it is not available to me because of confidentiality laws. In Nevada, I believe there were 7 donors in this age range and 300 to 400 throughout the entire United States over the last year. As far as how many minors died whose parents did not want their organs donated, I do not know. That statistic was not available to me.

#### Chair Dondero Loop:

Thank you very much. Most young people, when they are 16 and go for their driver's license, take a parent with them. That would be an optimum time to have that discussion, with your parent there to sign the paperwork with you.

Are there any additional questions?

# Assemblyman Eisen:

This is a comment more than a question in terms of offering some context. Currently, there are roughly 100,000 people nationwide who are on an organ recipient wait-list. It is estimated that somewhere between 10 and 20 of those people die every day awaiting organs. From the tragedy of an adolescent's death, we are talking about the opportunity to make that list one or two people shorter. That is a positive thing for us to offer.

Coming back to the issue of consent and parental involvement, what is being brought for consideration here is not a question of whether or not a 16-year-old

can become an organ donor. That is a different discussion altogether and one that has already been had and is enshrined in statute. It is a question of whether the decision that had been made could be reversed upon the death of an adolescent without, obviously, that adolescent's involvement in that decision. If they were to choose, while still alive, that they do not want to be an organ donor anymore they can do that, but this would be a matter of after their death. Someone would be reversing a decision that had already been made and documented.

# Chair Dondero Loop:

I know that even organ donations vary from state to state. Sometimes people end up moving so they can get on a shorter list in another state.

Additional questions or comments by the Committee?

# **Assemblywoman Benitez-Thompson:**

Thank you for your thinking of this bill and thank you to Assemblyman Carrillo for working with you. I can only imagine how intimidating it is to sit in front of a legislative body and get peppered by questions.

The bill does reference parents. If, for some reason, there is a guardianship involved instead of parents, would you be amenable to including the guardian in this?

#### Rachel Bowe:

This should include parents and guardians; anyone who is taking care of the minor, who has legal rights to the minor's care. The language should not just include parents but guardians, too.

#### **Assemblyman Hogan:**

I am very much in favor of a system that permits a young person to use his or her best judgment and to think in broad, generous terms about donating after his or her death. I would hate to see us include in the bill an express opportunity that would allow parents to overrule this kind and generous impulse that the young person had. I would not be comfortable with a provision that expressly said that if the parent, after the fact, decided to overrule, that they have every right to do that. I find that unacceptable.

# **Assemblyman Duncan:**

This is not in the proposed language in the bill, but what if an unemancipated minor who signed a refusal dies, and a parent of a minor who is reasonably available may revoke the minor's refusal. What are your thoughts about that; about overruling a minor's choice not to be an organ donor? I understand that

we want more organ donations, and I believe that is a good thing. However, I am curious because we are talking about a 16-year-old's choice. Do you think the parents should be able to overrule if the minor child stated he or she did not want to be an organ donor?

#### Rachel Bowe:

If the minor does not want to donate their organs, then, in that case, the parent or guardian should not be able to overturn that either. It should be equal on both ends of it. The minor's choice is the minor's choice. That is what this bill is for. Theoretically, it is to increase the number of organs available to the recipients on the waiting list; but if that minor explicitly states he or she does not want to donate their organs, then the parents should not overturn that either.

# **Chair Dondero Loop:**

Does anyone else have a question or a comment?

# Assemblywoman Spiegel:

You have raised some really thought-provoking questions for us. I was glad to hear you were open to the topic of having parents discussing this issue with their children before making and finalizing the decision about being organ donors. I am an organ donor, but I do not know how my mom feels about it. One of these days I may have the conversation with her, and partly because of this hearing, so thank you.

#### Chair Dondero Loop:

Are there any additional questions? Now, we will ask anyone in the audience who may be supporting this bill to come forward.

# Tracy Copeland, Private Citizen, Reno, Nevada:

I am a liver transplant recipient and the President of Sierra Nevada Donor Awareness, a small local nonprofit organization in northern Nevada that seeks to raise awareness of the tremendous need for organ and tissue donations while honoring our donor families. More importantly, for this discussion today, I am a parent. I echo your thoughts about how phenomenal this young lady is to have such a thought-provoking idea and to bring it forward to us all.

When Rachel first approached me, my first thought as a parent was to consider parental rights and how a parent wants to look after their minors. At what point do we consider our minor child to be an adult and capable of making his or her own decision? At that point I thought about this a lot. I thought about my daughter when she was 16 years old. I made a conscious decision as her mom that I felt she was mature enough to take on the responsibility of driving.

That is a huge privilege for our children. To consider that she is mature enough to make that decision to be a responsible driver, to be on the road, to be considering the laws and safety of herself and other individuals also tells me that she is mature enough to make this decision for organ and tissue donation. I wish that this is something parents and children would discuss. driver's education class the topic of organ and tissue donation is presented, so they do have that opportunity. Hopefully they are asking questions and being thoughtful in considering the subject. That is such a generous and incredible gift to give someone else. I think it would be an awful disservice to the memory of a child to not honor that child's wishes. When would a parent actually revoke that decision? Probably the most likely scenario would be a parent overcome with such unimaginable grief, as my donor family was, that they could not be faced with making that decision. To have that decision already made for them, to be able to say to them that their child had made that decision, would take an incredible burden off that parent when in that situation and dealing with so much grief.

# **Assemblyman Hickey:**

Given your experience with this, what do you think of the notion of somehow constructing a way whereby parents have this discussion, as has been suggested? Is that okay with you?

# **Tracy Copeland:**

Yes, I agree. If language could be provided or we could have the opportunity for discussion, so when a child under the age of 18 goes into the DMV, he or she has to bring a parent to sign certain documents. I was with my daughter when the question about donation on her application came up. We knew; we looked at that together. I would hope every parent would do that with their child. It is definitely a good avenue to take.

#### **Chair Dondero Loop:**

Any additional questions? [There was no response.]

# Michelle Middleton, Private Citizen, Carson City, Nevada:

In 1987 I was diagnosed with acute lymphocytic leukemia. I had chemotherapy for three years, but the chemotherapy damaged my heart. In 2002 I received the gift of life—a new heart. I am here today to speak on organ donation awareness. It has affected my family. I volunteer locally with two other organizations about organ donation awareness. I go to health fairs and speak to students in driver's education classes throughout the high schools. We encourage the students to talk to their parents. It is a question on the DMV driver's licenses, so when a minor applies, a parent is there to see what the child is signing.

My mom was waiting for a liver transplant, but has been taken off the list, so I have been on both sides of the transplant issue. The statistics are that over 100,000 people are waiting for transplants; but if it happens to your family, you are 100 percent of the statistics.

# **Assemblywoman Fiore:**

You are doing a wonderful job, but as a mom, the DMV argument the three of you have made is not good enough for me. I am okay if we can get the language for consent on both sides worked out. The language is a real stickler. Just getting a driver's license and clicking that you will be an organ donor, thinking that your mom or dad is okay with that, is not clear enough.

#### Chair Dondero Loop:

Additional questions or comments? Seeing no one else in support, do we have anyone in opposition? Anyone neutral? Seeing none, is there anything you would like to say before we close the hearing, Ms. Bowe?

#### Rachel Bowe:

I would like to thank you all for listening and considering these revisions. I have been working towards this for a very long time, and it means a lot to have you all here considering and listening to these arguments. I do believe that the language change to get consent from both parents and minor would be a great idea. While the family is sitting at the cubicle in the DMV deciding, it would be a great way to bring the topic up one more time before the paperwork is signed. I think that is a brilliant idea. While I had not considered that before, I am very glad you brought it up, because I think that is a great idea.

#### Chair Dondero Loop:

That is why we have these hearings. From one great idea, sometimes come more. I am sure we will have further discussions with Mr. Carrillo. Do you have a comment, Mr. Carrillo?

#### **Assemblyman Carrillo:**

I like to give credit where credit is due. When Rachel came to me with this idea about organ donation starting at 16 years of age, I was proud to see our younger generation stepping up and coming up with ideas for us. I understood that she was working on a Girl Scout project, but I also knew this was someone who wanted to make a difference. I would like to have further discussions with the Committee and with the Chair about any amendments that we could work with, because I believe this is something important. I know speaking before a committee can be intimidating, because it is for me, so I am sure it was for her. Rachel did a great job appearing up here in front of you. We ask you to please consider A.B. 144.

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Chair	Donderd	Loop
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Chair Dondero Loop:
We will close the hearing on <u>Assembly Bill 144</u>. Is there any public comment or comment from our Committee members before we adjourn? This meeting is adjourned [at 1:30 p.m.].

	RESPECTFULLY SUBMITTED:
	Terry Horgan Committee Secretary
APPROVED BY:	
Assemblywoman Marilyn Dondero Loop, Chair	_
DATE:	

# **EXHIBITS**

Committee Name: Committee on Health and Human Services

Date: March 15, 2013 Time of Meeting: 12:46 p.m.

Bill	Exhibit	Witness / Agency	Description
	Α		Agenda
	В		Attendance Roster