

ARIZONA STATE LEGISLATURE
Fiftieth Legislature – First Regular Session

**SENATE COMMITTEE ON HEALTHCARE AND MEDICAL LIABILITY REFORM
AND
HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES**

Minutes of Special Joint Meeting
Tuesday, June 14, 2011
Senate Hearing Room 109 -- 9:00 a.m.

Chairman Barto and Chairman Ash called the meeting of the respective Houses to order at 9:07 a.m. and attendance was noted by the secretary.

Members Present

Senators:

Gray	Nelson	Barto, Chairman
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Representatives:

Brophy McGee	Hobbs	Yee
Gonzales	Pierce	Ash, Chairman

Members Absent

Senators:

About	Lopez	Murphy, Vice-Chairman
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Representatives:

Heinz (excused)	Judd (excused)	Carter, Vice-Chairman (excused)
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Opening Remarks

Chairman Barto commented that she appreciates everyone's attendance to review items that there is no time to address during Session while Members are working on legislation.

Presentation: HIX Update

Don Hughes, Governor's Office of Health Insurance Exchange (HIX), related that 49 states plus Washington, D.C. and the four territories applied for and were awarded a planning grant of \$1 million in September 2010 to establish a HIX. Arizona has a strong and competitive health insurance market today and the intent is to build upon those strengths. The Governor's Office wants to plan a HIX that maximizes competition, consumer choice and the value people receive from health insurance products.

Mr. Hughes continued that the Affordable Care Act (ACA) allows states to create a state-based and state-run HIX or to defer to the federal government; however, a state-owned HIX is preferable for Arizona. The HIX should be a clearinghouse rather than an active purchaser so it does not become a second regulator and does not dominate the insurance market.

He indicated that according to the ACA, the HIX must be operational by January 1, 2014; however, the Office of Consumer Information and Insurance Oversight will be setting the initial open enrollment period, which he is hearing will be in the summer of 2013, so the HIX will need to be operational by that date. At that time, people will be able to access the HIX website to determine if they are interested and eligible for Medicaid, Kids Care or any other public program. The eligibility process currently takes 25 to 40 days, depending on the completeness of the application, so the computer system will need to be upgraded to allow enrollment to occur on a real-time basis.

In response to questions, Mr. Hughes provided the following information:

- Certain core area activities are required by the ACA so work groups were formed to address specific areas such as information technology (IT) infrastructure, plan management, tribal issues and brokers and agents. Workshops will be formed on public education and community outreach.
- A health insurance background analysis was conducted on Arizona's insurance market in order to determine the anticipated participation rate in the HIX:
 - About 1.2 million people are currently uninsured.
 - 3.3 to 3.4 million people are covered under employee-sponsored insurance.
 - 248,000 people have individual (non-group) plans.
 - 800,000 people are on Medicare and other military and federal health insurance programs.
- It is anticipated that 487,000 people will enroll in individual coverage through the HIX, a large portion of which will be from the existing individual (non-group) market who, depending on income, can take advantage of premium and cost-sharing subsidies that will only be obtained through the HIX.
- About 62,000 people are expected to move from current employer-sponsored insurance to the individual market.
- It is anticipated that about 67 percent of employers will drop health insurance coverage currently offered to employees and allow employees to take advantage of the premium subsidies in the HIX, which, in some instances, depending on income level and the employer, could be more economical for both parties. Also, a recent study estimates that 30 percent of employers will drop employer-sponsored insurance and have employees move to the HIX.
- An item under consideration to minimize that activity is a defined contribution option where the employer contributes a flat dollar amount and the employee will be able to access the Small Employer option of the HIX website to choose the health insurer and plan that best meets their needs, giving the employee more choice. This option would provide small employers an opportunity to control health insurance costs, and hopefully, give small employers not currently providing health insurance an affordable option to help employees obtain health insurance.
- The flat dollar amount to be paid by the employer would be set by the employer, but it would be the same for each employee; the state will not mandate the amount. If the

option chosen by the employee requires an additional contribution by the employee that is the employee's choice, which the HIX will be able to accommodate.

- By the end of the grant period, it is anticipated that \$850,000 of the \$1 million grant will have been spent. To date, grant money was used to pay for the background research, as well as an IT gap analysis to review current state IT resources and infrastructure, determine what is needed to operate a HIX and the cost, which is posted at www.azgovernor.gov/hix.
- The gap analysis includes different options for the state to consider in moving forward, including deferring to the federal government, building a new system from scratch, joining a regional multi-state HIX, borrowing from what other states have done or building the commercial portion of the HIX onto existing infrastructure at the Arizona Health Care Cost Containment System (AHCCCS) and Healthy Arizona.

In response to further questions, Mr. Hughes provided the following information:

- He does not have a list of companies granted an exemption from "Obamacare" since he is not involved in granting or applying for those waivers, which is a function of the U.S. Department of Health and Human Services.
- In order to develop a qualified health plan to sell on the HIX, an insurance company must be a Title 20 licensed health insurer in good standing with the Arizona Department of Insurance (DOI) and meet a list of other extensive requirements. States can impose additional requirements, but that will not be done in Arizona in order to make it easy for health insurers to qualify and provide as much choice as possible.
- The next rules package for the HIX has an approximate release date of June 20, 2011, but it is not known what those rules will be. There are many unanswered questions as to direction from the federal government, which has been one of the challenges in moving forward. Since it is a formal rule-making process, the rules cannot be discussed with the states for 60 days until the final rules are released.
- The ACA contains a provision to grandfather existing policies as of its effective date (March 23, 2010) so as long as there are no changes to the policy, and premiums and cost-sharing do not increase, individuals can generally retain their current policy.
- There will be changes and cuts in funding to the Medicare Advantage Program, some of which was restored, but that is being worked on in Washington, D.C.
- The HIX is intended to provide another vehicle for people to find affordable health insurance or enroll in commercial insurance and public health programs like Medicaid.
- An employer with more than 50 employees constitutes the category in which the penalty for not providing health insurance will apply; it will not apply to small employers. Some employers may make the business decision that it is less costly to pay the penalty, provide additional compensation to employees and send employees to the HIX where they will qualify for premium and out-of-pocket subsidies.
- In Massachusetts, the uninsured rate was reduced by half from 6 to 3 percent, which is a lot easier to accomplish than the 19 percent uninsured rate in Arizona, which, given the expected participation rate in the HIX, may be reduced to 11 percent. This will reduce cost-shifting from the uninsured to the insured.
- Massachusetts did not find employers dropping insurance coverage for active employees, particularly large employers; in fact, the number of employers providing health insurance slightly increased. The bulk of the reduction in the uninsured rate was due to substantial increases in the Medicaid program and heavily subsidized individual coverage. It is

anticipated that in Arizona there will be a substantial increase in the number of people who will qualify and enroll in AHCCCS because of the individual mandate and outreach and news coverage encouraging people to buy health insurance.

- Massachusetts' administrative costs to run its connector is about \$36 million, but it was built as a new and separate agency where everything is done in-house, which is not the direction planned for Arizona. The intent is to contract with private sector firms as much as possible, have minimal internal staff and contract with DOI to perform regulatory activities such as certifying qualified health plans, etc. Utah, which has a different vision for its HIX, experienced administrative costs of \$750,000 to \$800,000, which is about what is expected in Arizona. It will cost less to contract with existing vendors rather than leverage existing resources within state government.
- Louisiana publicly announced that it is going to defer to the federal government to run its HIX and returned the planning grant. Other states will probably do the same or be judged not ready in time.
- An option of doing nothing means deferring to the federal government, which is an option that is under review, but it involves turning over control of eligibility and enrollment for AHCCCS, KidsCare, Temporary Assistance for Needy Families (TANF) and Food Stamps, etc., as well as control of the health insurance market.
- Planning for the HIX does not compromise Arizona's position in the multi-state lawsuit against "Obamacare," which Arizona expects and hopes to win. Implementing the HIX has not been one of the issues raised in any of the three lawsuits at the Court of Appeals level. The Florida litigation was heard at the Court of Appeals last week and it is not known when a ruling will be made. When it moves to the U.S. Supreme Court, he does not know when a ruling will be made; however, it is prudent and responsible to continue to prepare to run the HIX because if nothing is done until the court rules, it will be too late to be ready in time. The IT infrastructure, just on the commercial side, through the procurement process, will probably take 18 months.
- If the Supreme Court rules to throw out the entire ACA, the decision can be made to stop work or move forward based on what is best for Arizona. If the Supreme Court only throws out the individual mandate and allows the rest of the Act to stand as the Virginia Court ruled, if nothing is done, there is not enough time to be ready to run a HIX and the federal government will take over.
- Research is being conducted on what is required under the ACA as far as enabling legislation. There has not yet been a decision to move forward with the next level of the grant; the Governor will probably make that decision this summer, but enabling legislation is not required. Legal authority to run a HIX in accordance with the ACA requirements will be needed for the grant after that.
- Consultants were hired to conduct the IT gap analysis and the background research, as well as to work with DOI on the insurance plan management aspect of the HIX. The Executive has the authority to award contracts now, but some items will probably require statutory authority.
- The next step is the establishment grant with two levels for which states can qualify:
 - Level 1: Extend the planning and initial startup of the HIX for another year (for which Arizona will likely apply).
 - Level 2: Provide plans from the present to the end of 2014 detailing the cost, enabling legislation and funding beyond 2014 (for which Arizona will not be applying).

- Research is being conducted to determine administrative costs to operate the HIX and the source of funding. Beginning January 1, 2015, the HIX must be self-sufficient because federal funds will no longer be provided. States have almost complete flexibility to determine necessary costs. Attempts will be made to minimize administrative costs and to contract with outside vendors as much as possible.

Senator Nelson indicated that in planning the HIX, the Governor's Office is not dealing with the hospital network, additional programs for which President Obama says "the only way to get any benefits from the feds is by cutting costs" or Medicare and Medicaid, for which he understands the federal government will be telling AHCCCS in a few years how many patients to take and what the state will pay for. He requested that staff compile an outline of issues for the Members to review because it has been a few months since he read information on "Obamacare" and he is not sure how it will impact the HIX.

Representative Brophy McGee wondered how HB2666 - health insurance; exchange, introduced last Session relates to the activities that Mr. Hughes is performing under the planning grant, which she would like to see included in the outline.

Chairman Barto indicated that she has many questions about the contracts the Governor's Office is planning to put in place before the lawsuit is decided, the impact it will have on the repeal of "Obamacare" and whether that will influence how the state acts. She would like more detail on the cost to the state and whether or not the competitive environment of a state HIX can be realized when federal government rules have not yet been promulgated. Perhaps the Members can come up with questions for a future meeting and time can be taken to delve further into more issues.

Mr. Hughes responded that he can provide additional information. The Governor made it clear that she is concerned and opposed to the ACA. She stated many times publicly and in letters to the White House and the Secretary of U.S. Health and Human Services that she is concerned about the expansion of Medicaid and the potential cost to the state, constitutionality of that expansion and the individual mandate. Arizona is part of the 26-state litigation that the states expect to win, but until that moves forward, Arizona's interest needs to be protected as best as possible by moving forward and minimizing the federal government's involvement.

Mr. Hughes added that Indiana, which is also one of the states involved in the lawsuit, recently received approval for a Level 1 establishment grant. The grant application stated that the ACA is unconstitutional, which is what the courts will find, but it is not known when a ruling will occur, so it is best to continue to plan for an Indiana-operated HIX to prevent the federal government from doing so.

Senator Gray announced that she received an email from Chuck Bassett indicating that 729 companies and cities requested waivers from "Obamacare."

Representative Brophy McGee commented that competitive choices and values pre-market and government do not go together.

Senator Nelson agreed, but surmised that it is important to move ahead with the planning grant on the assumption that the lawsuit may be lost, but it is also necessary to obtain answers in order

to inform constituents. He is Chairman of the Board of Directors at Maryvale Hospital, which is one of two top safety-net hospitals in the state. With elimination of disproportionate share (DSH) payments next year when the bulk of patients will only be paying what the federal government provides, some floors may be closed down and some hospitals may collapse, which impacts health care in rural and reservation areas. Without considering all of the factors, he does not know how a plan can be set up to meet Arizona's medical needs.

Chairman Barto stated that there are many questions in the cost benefit analysis as to whether a state or federal HIX is appropriate at this time.

Video Presentation: Eggsplottation

Chairman Barto stated that over the last few years, the Members heard concerns about the IVF (in vitro fertilization) industry and compromise legislation was passed, but she believes it is necessary to study the issue further. She acknowledged the presence in the audience of two people featured in the video, Dr. Jennifer Schneider and Dr. Suzanne Parisian.

The video entitled "Eggsplottation" was viewed, which notes the practices used by the fertility industry to encourage young, healthy, college-aged women to become egg donors. Three women in the film talk about their experiences during the egg donation process that involved high doses of fertility drugs and egg retrieval surgery and resulted in life-threatening complications.

Responses

Dr. Marcelle I. Cedars, Professor, Obstetrics, Gynecology and Reproductive Sciences; Director, Division of Reproductive Endocrinology and Infertility and University of California, San Francisco (UCSF) In Vitro Fertilization Program, read stories from patients who utilized egg donor resources. She stated that it is important to put the information provided in the video into context. Complications do happen when women donate eggs, as with all medical procedures, but when the Food and Drug Administration (FDA) reviews a drug or procedure, it evaluates safety and effectiveness. Egg donation is probably the most effective procedure because the most recent national data from the Centers for Disease Control (CDC) suggests that the success rate of an egg donor cycle is 55 percent, whereas the success rate of a fertile couple becoming pregnant in any given month is about 20 percent. Regarding safety, there are risks and there have been studies, but it is important to realize that the drugs and procedures a donor goes through are exactly the same for the IVF patient up to the point of egg retrieval.

Dr. Cedars stated that studies involving the review of 10,000 women addressed the following risks:

- Ovarian hyperstimulation (OHS), which is when the ovaries are overstimulated, happens to all patients involved in IVF to bring more eggs to maturity, so she tells all of the women to expect to be full and bloated for a week to 10 days after the procedure.
- The severe form of OHS requiring hospitalization occurs in about 25 women per 10,000. It is actually four times more common if a woman becomes pregnant because human chorionic gonadotropin (HCG) from the pregnancy hormone keeps the ovary stimulated, so the severe form is actually more common in patients who undergo a transfer. If a

patient is deemed at risk of OHS, the recommendation is made to retrieve, fertilize and freeze the eggs, but not perform a transfer.

- The risk of death from OHS is about 1 per 400,000 to 1 per 500,000, so while it can occur, it is very rare.
- In terms of bleeding, the risk is approximately 3 per 1,000 with about 10 per 10,000 who actually have a serious complication requiring surgery.
- Regarding torsion, or twisting of the ovary, the risk is rare, occurring in 24 per 100,000 cycles of IVF.
- A death occurred from one egg retrieval in Israel when the procedure was new, which she tells donors patients about to provide the worst-case scenario for what can happen even though it most likely will not happen to them.
- One of the problems in studying cancer risk is that someone may have an exposure, but not have an event for many years. The first papers published in the early 1990s suggested there was a risk between fertility drugs and ovarian cancer. Subsequent studies (including a series of large studies from Denmark of over 50,000 women where there is a very good health care system, IVF is used more and everyone goes into a database), indicated that no risk of cancer from the fertility drugs has been established. It may take another several decades to obtain what some would call complete data, but there is currently good and long-term data about follow-up and safety.
- These procedures do have some risks, but the risks are low. It is important that donors and recipients, and any patient who undergoes a procedure, are aware of the risks. With all procedures, there is an issue of risk and benefit.
- To put the risks in context, for a hysterectomy, one of the most common procedures performed on women, the risk of bleeding requiring a transfusion is 2 to 3 percent, which is ten times higher than the risk of egg retrieval.
- The risk of a serious complication with a hernia procedure, which is a common surgical procedure men may undergo, is about 3 percent, again ten-fold higher than the risk that has been associated with an IVF cycle or egg retrieval.

In response to questions, Dr. Cedars provided the following information:

- Being fertile provides protection against the hormone drugs given to egg donors; much of the increased risk of cancer identified in the early 1990s involved a comparison of women who took fertility drugs to the general population, and women who are infertile have an increased risk of breast, uterine and ovarian cancer.
- The drugs, follicle-stimulating hormone (FSH) and luteinizing hormone (LH) or Lutoprin, which are given to women, are identical to hormones produced by the brain. She is not sure there is evidence suggesting that the risk of taking the hormones for a donor is different than for a patient. In fact, donors receive lower doses because the intent is not to stimulate all of the eggs of the donor as in the patient.
- The same process is used for the donor and IVF patient so the doses and protocols used have evolved over time. Protocols have been compared in randomized trials to decrease the risk of OHS by using different types of medications; there have been trials for donors and non-donors for types of protocols and dosing.
- One of the newer techniques is to use gonadotropin-releasing hormone (GnRH) agonists to trigger final maturation of the egg instead of HCG, which remains in the body for a long time and increases the risk of OHS. A GnRH agonist stimulates the body to release LH, which has a very short half-life and some studies suggest there is no risk of OHS.

When risks are so rare, even studies of 500 women may not show a risk, but there may still be an outlier patient who has a complication.

- Lupron is a GnRH agonist used in gynecology for treatment of endometriosis and uterine fibroids. It has been used in IVF since the mid-1980s to stimulate or suppress LH. Studies have been done on Lupron with women who have uterine fibroids or endometriosis who are frequently fertile and may be on the medication from three to twelve months at the same or higher doses than for egg donors who are typically treated for two to four weeks.
- Egg donors are typically tracked at least until they get their next period to make sure the ovaries are back to normal size. As with all medical procedures, a better way is needed to evaluate the patients, but there is more follow-up and oversight with IVF than other procedures. National data is recorded of not only success rates, but actually live birth rates, so patients are followed for the next year for purposes of their health, the potential of children who may want to meet donors and potential long-term complications.
- There has been a push to have a donor registry, but the specifics have not been fully worked out. A government-mandated registry would be difficult because of the need for resources. Several societies and psychologists are motivated to begin a registry for egg and sperm donors.
- Attempts were made to statistically calculate, based on the size of a population, how many children are conceived from the same donor, which is more of an issue for sperm donors than egg donors, but a donor registry would ensure there are no consanguineous marriages.
- A donor registry would allow for sharing of medical and genetic information between the donor and child, as long as the information is transmitted in accordance with the Health Insurance Portability and Accountability Act (HIPAA).
- The American Society for Reproductive Medicine (ASRM) and the Society of Assisted Reproductive Technology (SART) have guidelines and recommendations for the amount an egg donor is compensated for the process of egg donation. The quotes in the film of \$25,000 and \$100,000 are above the recommended upper level limit of ASRM of \$5,000, except in extenuating circumstances, which has to do with the difference in price between the two coasts.
- ASRM and SART argue against compensation based on SAT scores, class rank and the number of donations or eggs produced because none of those are involved in the process. The payment should be for the process and not for the product. ASRM recently started to remove agencies that do not follow those guidelines from its list of approved and accepted agencies. In order to be members of SART, physicians must agree in writing to follow its recommendations.
- All donors have a separate health insurance policy purchased by the receiving couple or through the agency to cover any complications of the IVF procedure with about a two-month window after the process.
- SART is a special society under the umbrella of the ASRM that makes most of the guidelines and recommendations for assisted reproduction, which receive final approval by the ASRM Board.
- A 10 percent random audit of all fertility programs is conducted by the Centers for Disease Control (CDC) and SART, including donor compensation and the website. To be a member, fertility programs must agree in writing to follow SART guidelines.

- The egg donor process is arduous. Less than 10 percent of women who apply are accepted into the donor program and applicants go through a rigorous process including an evaluation of their medical history, a meeting with a genetic counselor for full pedigree, a meeting with psychologists for formal psychological testing, discussion of their motivations and understanding of the process, and a physical exam with a physician. FDA guidelines for screening donors must be followed. There is also a consent process in which the short-term risks from the point of pain at the injection site to bleeding, death and OHS are discussed. Some patients choose not to donate eggs and some are turned away because there may be a potential health risk.
- It is difficult to track egg donors in the U.S. for 10 to 30 years to make sure there are no long-term consequences because the strongest principle in the U.S. is autonomy. It is easier in a Scandinavian country where there is a good database and everyone is in the system. More long-term studies are needed, but she does not know how it should be done.
- ASRM and SART are involved in discussions about setting up a donor registry.

Senator Barto acknowledged the need to look at donor-conceived children and their rights on the same level as adopted children by keeping records and making the records available. She said she read about donor-conceived children who feel very alone and experience emotional pain as a result of not being able to locate their parents and not knowing their genetic history. She read excerpts from *Newsweek* about Alana S., a donor-conceived person who created www.anonymousus.org for donors, their families and medical professionals as a healing resource, and Lindsay Greenawalt, another donor-conceived person who created www.confessionsofacryokid.com.

Representative Brophy McGee stated that a registry could also extend to children whose mothers are not sure of the identity of their father or children whose parents are protective of their medical history.

Chairman Barto noted that confidential intermediaries can often find out information through the courts and other venues, but indicated that this issue seems to need more study.

Senator Nelson related that tests are conducted on newborns by the State Laboratory, and if the results are recorded electronically, it would be simple to begin a database moving forward. He asked if a child wants to know information, who will consider the ramifications and determine whether the child has the right to know and at what age. Research is necessary not only about the legal aspects, but also the ramifications to the individual child and parents.

Senator Gray asked if donors are willing to provide information for the child if the parents are willing to accept it.

Dr. Cedars replied that egg donors are asked about the type of communication they want, i.e., meet the receiving couple or exchange letters. Fertility companies obtain all of the medical and genetic history. The psychologist meets with the recipient couple and donor to discuss what is currently required and advises that release of the information may be relaxed in the future so confidentiality is not guaranteed. It is very common to at least exchange letters, mementos or pictures.

Senator Nelson said that does not include Child Protective Services or other agencies.

Chairman Barto stated that one of the biggest differences with IVF and egg donation is that life is intentionally created and there are competing genetic history rights as opposed to adoption.

In response to further questions, Dr. Cedars provided the following information:

- About 10 to 15 eggs are extracted from the egg donor, which is typically enough for a pregnancy and to freeze some in the event the couple wishes to have two children who are genetically related without the egg donor going through another cycle. Only one, or at most, two embryos are transferred from a fertile donor because the pregnancy rate is so high; about 50 percent of the eggs retrieved are fertilized.
- If a couple wants only one baby, the couple will request that not all of the eggs be inseminated, but couples typically want to build a family of children who are related so remaining eggs are frozen to use in the future for pregnancy.
- Couples must choose and sign for an option ahead of time in the event the frozen eggs are not used due to divorce, etc., to have the eggs discarded, donated to another infertile couple or donated to research. The eggs cannot be sold.
- If the couple wants the frozen eggs discarded, they are thawed and allowed to die. If the couple wants to donate frozen eggs to research, the couple chooses the type of research, i.e., the study of infertility, stem cell research or other research where the eggs go into a tissue bank and programs submit a proposal that is approved by the Clinical Institutional Review Board for Human Research and the Human Gamete, Embryo and Stem Cell Research Committee. If the couple chooses to donate frozen eggs to another couple, the eggs go into a pool with a program in which a counselor and psychologist match embryos for donation. The donor couple must go through FDA testing and other requirements in order to donate the frozen eggs, but are not compensated.

Jennifer Lahl, President, Center for Bioethics and Culture Network, provided the following handouts:

- Case Report by Jennifer Schneider, M.D., Ph.D., titled *Fatal colon cancer in a young egg donor: A physician mother's call for follow-up and research on the long-term risks of ovarian stimulation* (Attachment 1).
- Testimony at Congressional Briefing on November 14, 2007 by Dr. Jennifer Schneider on human egg trafficking (Attachment 2).

Ms. Lahl stated that the video was released around the country less than 10 months ago and it has been a great bridge builder with coalitions left and right. This is not a pro-life issue; it is a pro-women issue. The film was shown in Prague and will be shown in Sweden because it applies to women around the globe. She would like to see the studies mentioned because her research indicates that long-term studies specifically on egg donors have not been done. The European Society of Human Reproduction, a large data-collecting warehouse for European women, produced a report a month ago that specifically addresses third-party reproduction and tourism because it is possible to fly all around the world to obtain eggs and sperm. The report states that data available on egg donation is scarce.

Ms. Lahl stated that the video showed three women's stories and since its release, she was contacted by nearly two dozen women whom she is interviewing to document their stories. Cindy, the young Asian woman in the film is now married. She was having a difficult time becoming pregnant, but she is now pregnant with twins; however, she recently found out that she has a medical condition her doctor believes she obtained from an emergency blood transfusion during the egg retrieval surgery. She was recently admitted to the hospital for an emergency procedure to suture the cervix closed to keep the babies in the womb and she is on bed rest for the remainder of the pregnancy. All three of the women in the film went through a long, arduous screening process and were otherwise young, healthy women.

Ms. Lahl made the following policy recommendations:

- Institute an independent regulatory body to establish a voluntary tracking mechanism.
- Curb the placement and content of egg donation ads, including a prominent disclaimer.
- Eliminate compensation because people will take risks if there is a financial need.
- Fill the information void for consent purposes primarily through peer review medical research.
- Require fertility clinics to retain data for an extensive period of time.
- Place a moratorium on all egg donor practices until more data is available.

Senator Gray asked if a woman who already has children and wants to become an egg donor should be compensated for the care of her children. Ms. Lahl replied that someone who donates a kidney, which takes a lot of time and involves an arduous recovery and risk, is not compensated. The risks of egg donation are mitigated because of the money being offered to compensate.

In response to further questions, Ms. Lahl provided the following information:

- From chat rooms and forums she has found that many egg donors do not even see a doctor until the day of the egg retrieval. Nurses are under the same requirements as doctors, but many times the women in egg broker agencies are not nurses, but former egg donors interested in helping women have babies. She noted that one of the women in the movie received the hormones in the mail and was told over the phone how to draw the medication and give herself an injection, which she had to get her boyfriend to do. There is probably a lot of this done "under the table" but she has no sense of the amount because the industry is largely unregulated.

Senator Gray asked if the definition of *eggsplait* as related in the video (to plunder, pillage, rob, despoil, fleece, and strip ruthlessly a young woman of her eggs, by means of fraud, coercion or deception, to be used selfishly for another's gain, with a total lack of regard for the well-being of the donor) applies to any egg donor. Ms. Lahl opined that many women who donated eggs have been *eggsplaited*, but she would not say it applies to every woman who donates eggs.

In response to a question, Ms. Lahl clarified that she does not want IVF to be stopped, but she recommends a moratorium on egg donation involving otherwise young, healthy women, for which studies have not been properly conducted, in order to adequately give informed consent and to remove compensation so women can freely hear about and agree to accept the risks. She added another recommendation:

- Remove anonymity so biological genetic information is available to donor-conceived children in the future.

In response to questions, Ms. Lahl provided the following information:

- As to whether there should be limits on the number of egg retrievals, she interviewed many women who experienced significant harm the first and only time, so for them it did not bode well to donate once.
- A 2011 study showed that women who receive a donated egg and have a child from the donation are at significant increased risk of maternal morbidity as it relates to pregnancy-induced hypertension, which impacts the health of the pregnant woman and the unborn child and results in increased health costs because of a high-risk pregnancy. The article indicated that this seems to be a rejection issue. She is not against infertile women, but she does not want another woman harmed to solve their problem, which is why she recommended a moratorium until further study is done.
- Europeans have done an excellent job in data collection, but have a paltry amount of data pertaining to egg donors.
- Eggs cannot be sold in Canada or the United Kingdom, but she interviewed an egg donor who said about 50 percent of egg donors are Canadian women who are flown to the U.S., which is included as part of the compensation.

Chairman Barto reiterated the fact that she appreciates everyone's attendance. She indicated that more information will be sent out on this issue and encouraged the Members to do some research in order to work on legislation.

Chairman Ash announced that Representatives Heinz, Judd and Carter asked to be excused because of other commitments.

Without objection, the meeting adjourned at 12:11 p.m.

Linda Taylor, Committee Secretary
June 23, 2011

(Original minutes, attachments and audio on file in the Chief Clerk's Office; video archives available at <http://www.azleg.gov>)