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HOUSE OF REPRESENTATIVES

JUDICIARY COMMITTEE

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TUESDAY, MAY 13, 2014
10:00 A.M.

PUBLIC HEARING
SUB COMMITTEE ON FAMILY LAW - HB 30 DONATE LIFE PA

BEFORE: HONORABLE BRYAN CUTLER, MAJORITY CHAIRMAN
HONORABLE SHERYL M. DELOZIER
HONORABLE JOSEPH T. HACKETT
HONORABLE MARK KELLER
HONORABLE MIKE REGAN
HONORABLE RICK SACCONE
HONORABLE THOMAS CALTAGIRONE, MINORITY CHAIRMAN
HONORABLE VANESSA LOWERY BROWN
HONORABLE DOM COSTA
HONORABLE MADELEINE DEAN

ALSO PRESENT:
HONORABLE ROBERT W. GODSHALL
HONORABLE KERRY A. BENNINGHOFF
HONORABLE JOSEPH PETRARCA

COMMITTEE STAFF PRESENT:

THOMAS DYMEK, COUNSEL
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KAREN DALTON, COUNSEL
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I N D E X

P R O C E E D I N G S

CHAIRMAN CUTLER: Good morning, everyone. We'll go ahead and call the subcommittee hearing to order. My name's Bryan Cutler. I'm the representative for the 100th District. We'll begin by letting all the members state who they are and where they're from and what their particular interest is in the issue, if they so choose. Because I know that we have some other members who aren't regular members of the Committee but asked to sit in.

Additionally, I'd like to note that this meeting is being recorded, as we always do at the beginning of all the Judiciary Committee meetings, and it will be available later. So with that, we'll go ahead, and I will start to my right with Representative Delozier.

REPRESENTATIVE DELOZIER: Thank you very much. Sheryl Delozier, representing Cumberland County. And this issue, in and of itself, is very interesting to me, and very important, as an organ donor myself. And my family, it's something that has been very important, so many people see the benefits of organ donation. So thank you for the testimony, and I look forward to hearing something today. Thank you.

REPRESENTATIVE KELLER: Mark Keller. I represent the 86th District, which is Perry and Franklin County. And personal involvement would be with the fact that I have family members who have actually donated, so that's why I have an

interest.

REPRESENTATIVE COSTA: Good morning. Dom Costa, Allegheny County, City of Pittsburgh, northern suburbs, 21st District.

ATTORNEY VITALE: Dave Vitale, Democrat Executive Director.

REPRESENTATIVE CALTAGIRONE: Tom Caltagirone, 127th District, City of Reading. And I am an organ donor. Thank you.

ATTORNEY DYMEK: Tom Dymek, Executive Director.

ATTORNEY DALTON: Karen Dalton, Counsel to Representative Marsico.

REPRESENTATIVE SACCONE: Rick Saccone with 39th District of Southern Allegheny and Northern Washington Counties.

REPRESENTATIVE BROWN: Representative Vanessa Lowery Brown, Philadelphia County.

CHAIRMAN GODSHALL: This is Representative Godshall from Montgomery County.

CHAIRMAN CUTLER: Thank you, Chairman Godshall. We'll give Chairman Godshall an opportunity to speak in a little bit, because he certainly has a different perspective than many of us.

One of the things that I wanted to highlight was really the desire to get all of the stakeholders together to

hear their concerns, because if you go back with our Organ Law originally, we certainly were a leader in the nation. And I would point out now that as technology has advanced, and unfortunately the waiting lists have grown, the laws around us have simply passed us by.

I'm going to highlight some of the areas where I think all law could be updated, hear the concerns with the stakeholders who have any concerns in regards to those updates and those potential solutions, because I think it's important to always vet fully any issue that we would have before us.

I'd like to first recognize Representative Petrarca from the 55th District. He will be coming and sharing jointly, and then we'll invite him to join the Committee since he is the prime sponsor of the Bill. While he's taking his seat, I'll go ahead and briefly share my own story.

My uncle was twice a recipient of a kidney transplant. He personally received one from his son, unfortunately, it did not take. And then several years later he was also the recipient of an accident victim's kidney. That was kind of the beginning of our journey in this realm, understanding the complex situations that oftentimes are very tragic on one side of the equation, but yet give hope to other families. And that is something that I think is the balance that we should always strive to strike as policymakers. With that, I'll recognize Representative Petrarca for his opening

statements. Thank you.

REPRESENTATIVE PETRARCA: Thank you, Chairman Cutler. I'd like to also thank Chairman Marsico, Chairman Caltagirone and members of the Committee, and other honored representatives and guests for being here today.

To me, House Bill 30 Donate Life PA Act is the most important piece of legislation that we'll deal with this session. When you look at what's going on in Pennsylvania with organ donation, we have over 8,000 people on the waiting list. And every year in Pennsylvania, about 450 people on that list who are waiting for the phone call that a suitable organ is available die, unfortunately.

Organ donation is very important, to me. As some of you may know, I followed my father into the legislature. He served his last two terms with a transplanted kidney, and in 1994 was instrumental in the passage of Act 102 that set up Pennsylvania's organ donation law. And that law was, at the time, groundbreaking. A groundbreaking piece of legislation, looked at and used by many --- many other states in this nation as model legislation. Also, viewed by many other countries as a piece of legislation that they would like to try to pass in their countries for organ donation.

The goal --- the goal of House Bill 30 is simple. It's to make available more organs for those folks in need. Simple. That is the goal of House Bill 30. And I would like

to say that there's companion legislation in the Senate, Senate Bill 850. And that legislation is a little further in the process, in the Senate having gone through a hearing and action in the Senate Judiciary Committee. And the goal of House Bill 30 --- or what will happen in House Bill 30, if this Bill is acted upon by the Judiciary Committee, we will try to amend the House Bill so that it matches what is going on with the Senate Bill. So the Bills are slightly different, slightly different at this time.

The intent of --- again, other intent of House Bill 30 was to create a comprehensive framework of public education regarding organ donation to clarify the methods of how an anatomical gift is donated. And to update current law with best clinical practices to put us, Pennsylvania, in line with the Uniform Anatomical Gift Act. That's a piece of legislation that has been adopted by, I believe, 45 states in this country.

And as Representative Cutler said, we, in Pennsylvania, feel that in a sense we are falling behind. And it's very difficult for us in Pennsylvania having, again, model legislation a number of years ago, to be in a situation where, quite frankly, not enough organs are available for those in need. And with the medical --- with the medical advances today, the healthcare community is ready, willing and waiting to take care of as many people --- as many people as possible. And when you look at those, those on waiting lists, certainly

can be viewed as some of our most vulnerable, some of our most vulnerable citizens.

And we, as you know, as elected representatives, when we come to Harrisburg, we try to fix things. A number of problems in Pennsylvania, a number of things we try to deal with on a daily/weekly basis to try to correct --- correct an injustice or right a wrong. And a lot of those things we can't fix. Organ donation is something we can fix. You know, when I look at this, all we need to do is pass a piece of legislation to allow these folks a second chance at life.

And you know, we've all --- we've all been touched by organ donation. You know, family, friends, loved ones, and you know, it's very difficult, as I remember my family waiting --- waiting for my father's kidney transplant. You just wait for that telephone to ring. Every day, every night, you know, you're waiting for that phone to ring.

So obviously, I think we have some great testifiers here today, panels that know a lot --- certainly a lot about organ donation. And I have served on our organ donation advisory committee, since its inception in 1995 then appointed by Governor Tom Ridge. And you know, the folks I have met in the organ donation community, extremely knowledgeable, extremely professional, and quite frankly, some of the nicest people that you'll ever want to meet.

Be it our Organ Procurement Organizations, folks at

the Department of Health, Transportation, Education, donor families, recipient families and folks, quite frankly, on the waiting list. So again, hopefully this will be a very productive hearing. And after that, maybe --- or again, I'd like to see this legislation moved so that we can provide these folks that second chance and allow them to hear that telephone ring. Thank you, Chairman.

CHAIRMAN CUTLER: Thank you, Representative Petrarca. As I stated earlier, please feel free to join the Committee to hear the panel --- or the panels, rather, as we move forward. While he's taking his seat, I'll invite Chairman Godshall to, briefly, share his experiences.

CHAIRMAN GODSHALL: Thank you, Mr. Chairman. I'll only take a minute or two. I guess today my figure is so there's probably closer to 9,000 people on the waiting list in Pennsylvania, and unfortunately, there's people added every day, and there's people subtracted, unfortunately, every day.

I witnessed my neighbor pass away waiting for a liver transplant a couple years ago. And I know that most --- a lot of those people on the waiting list were for kidney. And I had some figures from the National Kidney Registration Foundation pertaining to Medicare. The minimum was $71,000 --- now, this was a couple years ago --- a year to maintain an individual on dialysis versus $10,000 a year on anti-rejection. And so --- also there was a white paper put out by University

of Pennsylvania's Wharton School demonstrating how an additional 1,500 to 2,000 living donor transplants annually could save the American healthcare system upward to $100 billion over the next decade. Mainly dealing with the kidney end of it at that point.

I don't like to be personal, but my own --- this issue is personal with me. I know firsthand how critical this legislation is to those whose lives depend on another person's willingness to donate an organ or bone marrow. I underwent a bone marrow transplant in 2005, upon learning that I had multiple myeloma, a deadly cancer with no cure.

A living donor saved my life. The transplant I received sustained me long enough for a new drug to come on the market that now controls my disease and remission. And I do remember when I talked to the people down at the University of Pennsylvania pertaining to the bone marrow transplant, they said they wouldn't do it. And I contacted a number of other institutions, and I got the same answer, that according to my age, it was too dangerous for me to go through the transplant at that time. Well, they also told me I had a year to live. And you know, I thought, well, what am I going to lose, you know. I might lose a year.

So I took that chance, and fortunately, got a bone marrow transplant. Very little rejection, and a number of years later, ten years later, I'm here and still in the House

of Representatives. So it's sometimes --- you know, I couldn't believe it when I was told that I had this multiple myeloma. I showed no symptoms whatsoever, but I was told that this was it for me.

So all I can say is I know how important transplants are to people that need them, because I was one of the one that needed them. So I say thank you to the Committee for taking this up, but it's a vital situation that should be looked at, and really something that we really ought to get involved in and do something about. So I just want to say thank you for the opportunity to say a few words.

CHAIRMAN CUTLER: Thank you, Chairman Godshall. With that, we'll invite the first panel to go ahead and proceed to the front here. It's Howard M. Nathan, President and CEO of Gift of Life, and then Richard Hasz, who is the Vice-President of Clinical Services. Gentlemen, thank you for joining us this morning.

Just kind of as a start to set the tone, I will highlight that obviously we have a large itinerary before us and a very deep and very lengthy set of testimony. To the extent that we can do our best to stay on schedule, I would certainly appreciate it. Thank you, gentlemen. You may proceed.

MR. NATHAN: Thanks, Chairman Cutler. And thanks Chairman Caltagirone, and the Committee's support for having

the hearing. And thanks to Representative Petrarca for helping us develop the Bill, and Representative Godshall for his story. And it is compelling to see that lives are saved through others' gifts.

So my name is Howard Nathan. I'm the President and CEO of Gift of Life Donor Program. It's the Federal Designated Organ Procurement Organization for the eastern half of Pennsylvania. And this map shows the designation by the federal government through CMS, to designate Gift of Life, and in the western half is Center for Organ Recovery and Education. You have written testimony from Susan Stewart, my colleague. And there's several folks in the audience, Misty Enos and T.J. Roser from C.O.R.E.

Gift of Life has been an organ procurement organization and serves 15 transplant centers in the eastern half of the state, and we've been in existence for 40 years. I've been a part of the organization for going on 36 years. During my tenure, Pennsylvania has really been the world's leader in organ donation and transplantation. But the reason for the House Bill is we just haven't done enough. We've got to save more lives, because people are dying every year. You heard from Representative Godshall that more than 400 people died last year waiting for a transplant.

When you look at the waiting list, you can see that the waiting list consist of many people. This waiting list in

the state is large. Last year there were only 1,500 transplants in 18 transplant centers in our area, in our state. So we have to wait sometimes six, seven years for a kidney transplant.

When you look at it nationally, one person is added to the waiting list every ten minutes. Eighteen (18) people die everyday. And if you'd look at the national waiting list, 122,000 people are waiting.

When you look at Pennsylvania, and you look at the statistics on who can become a donor, it's shocking. 123,000 people die every year in our state, but only 665 people were donors last year. 665 was translated into the 1,500 transplants. It's a rare event. Donation, when a family says yes, is a unique event and a rare event.

The reason is that someone has to be declared brain dead to be an organ donor, and that only occurs less than one percent of the time for someone who ends up in a situation, in a hospital in a critical care unit. So that's really one of the major reasons that we can't lose just one donor. We want to make sure that if a family is willing to say yes, or an individual has already said yes on the donor designation, that person should become a donor. And we can work together to make sure that happens.

This is what it looks like in terms of the gap. So since 1994, the number of people who've had transplants

actually has doubled, so we've done pretty well. But the waiting list, which is the blue, represents the people waiting just in our Gift of Life region. So the gap is huge, and that's what we're trying to combat.

You should know that organ procurement organizations are highly regulated. First, the Center for Medicaid and Medicare Services oversees us and audits us and makes sure that we follow policy every four years. The United Network for Organ Sharing audits us, which is the network that links all organ procurement organizations and transplant networks, audits us every day, and reviews us every three years. So this just shows you ---.

And the Food and Drug Administration monitors us all the time, particularly for tissue donation. So the bottom line is that we're highly regulated by federal authorities and then there's voluntary groups that we get accredited by.

Why pass the Bill? Well, I think it's pretty compelling, and we'll hear some pretty compelling stories from people in the audience who are waiting for transplant and people who have given the gift. What the law does is basically three major components.

It helps us unify clinical best practices all across Pennsylvania. In hospitals, 175 hospitals. It basically aligns the donation hierarchy for consent to make sure it aligns with what current practices. And it provides for

suitability testing for patients who could be potential donors.

The second thing it does is it enhances public education and awareness with strong public education programs, particularly in high schools, while high school students are getting their driver's license. This may mean more designations and in the long run more donors. The people understand what donation's about, and they can say yes to donation.

It also helps nursing schools and medical schools have education to educate our healthcare professionals. So they understand the circumstances of organ and tissue donation and that they can carry it out in their work and make sure that families are treated with respect and dignity. And we approach it to families in a sensitive way in conjunction with the organ procurement organization.

It promotes consistency of practice of the coroner's system across Pennsylvania with regard to evaluating organ donation for victims of crime. The practice currently is inconsistent, and some donors who want to donate are turned down. And this varies from county to county and from election to election. We'll hear later from a medical examiner to talk about this system and how it occurs in his jurisdiction.

In most places, in most times organ donation is permitted, but children, in particular --- and I passed on the slide, but children who could be donors, who could save other

children's lives, children who are waiting for a transplant die four times as much as adults waiting. So if a child's organ is turned down by a coroner, another child's life, as many as eight children may be bypassed.

There's a myth going on about viable transplantation organs that may be inconsistent with autopsy. It's far from the truth. The decision to turn down an organ by a coroner is done without actual physical evidence of the donor organ. We want to change that. We want to make sure that if there's some reason to turn down an organ, that there's physical evidence that they look at and come to the hospital to take a look.

It does not change their authority at all. They have full jurisdiction over a body. This law only enhances the way that donation and autopsy and forensic evidence can be compatible to work together to make sure that both can be carried out effectively.

So with House Bill 30, I hope that you'll see that this can change lives, and that many families' lives hang in the balance waiting for that call as Representative Godshall has talked about. So Gift of Life Donor Program and C.O.R.E. emphatically support this Bill so that we can change lives in our state. Thank you very much.

MR. HASZ: Thank you to the Committee as well. I'm Richard Hasz. I'm the Vice-President of Clinical Services for Gift of Life. I've been coordinating organ and tissue donation

and working with families to meet their wishes for over 23 years.

The purpose of my testimony today is to provide the Committee with an overview of the current donation process and where it intersects with current law and how the proposed House Bill 30 will improve the system and help save additional lives.

I'm going to, for illustrative purposes, in my presentation, walk you through the donation process with the understanding that many of these steps don't always happen in this linear fashion. However, we're going to walk through it as if it did for the purposes of today's talk.

Under current donation protocols and hospitals under Pennsylvania Act 102, donation starts with a referral of a potential donor from an acute care hospital to a federally designated organ procurement organization, either C.O.R.E. or Gift of Life.

Under this current law and now codified and federal regulation based on the improvement in the donation over 20 years, hospitals are required to notify us of all patients' deaths in order to ensure that patients are properly evaluated for the potential for organ and tissue donation, and that families are provided that opportunity to donate.

Organ donation, as Howard said, however, is a very rare event. It's limited to a particular pool of patients who have suffered a very acute neurologic devastating injury.

They're in a hospital intensive care unit, on a ventilator and have been declared dead based on neurologic function.

As Howard has testified, this occurs only in one to two percent of all deaths that occur. So to become an organ donor takes it more than just to be on your driver's license. You have to die in a particular way, a devastating neurologic injury in an intensive care unit on a ventilator.

The rule of the organ procurement organization really is then to evaluate what opportunities are available for a family to donate. And to do this, we do it by communicating with the patient's attending physician, their healthcare team, the nurses taking care of that patient throughout their hospital course, reviewing medical records and looking at physician-directed laboratory results.

Passage of House Bill 30 will further hardwire this process by allowing for timely evaluation and testing. Next slide, Howard.

It is important to know that brain death has been recognized as death since 1968 with a publication of Harvard brain death criteria, and has been codified into law in Pennsylvania with the Uniform Determination of Death Act. House Bill 30 does not change this.

Every hospital in Pennsylvania has a brain death policy that complies with this state's statute. And these policies include strict guidelines in testing that's made to

determine that a patient has been declared dead. It's important to know, both by statute and by practice that OPOs and transplant physicians are prohibited by state and federal oversight from being involved in the declaration of death.

When brain death testing is initiated, OPOs will make an initial call to the medical examiner and coroner to begin the process to evaluate that patient's release for donation and transplantation. And I'll talk a little bit further about this in my testimony. Next slide, Howard. Next slide.

As you can imagine, the request for organ donation comes at one of the worst possible times for a family. Soon after they have received the news that their loved one has died, they will be meeting with a trained representative from one of the organ procurement organizations. This professional will work with them and to begin in guiding them on their grief journey on how they can make a decision that's informed about donation and their ability to help others through transplantation.

It's important to recognize this approach requires sensitivity to the circumstances of the decedent's death, to the religious views of the donor and the donor's family, and to the cultural views. And the vital recognition that a family's decision will be respected.

Coordinators are experienced healthcare

professionals with years of backgrounds in the ICU nursing or para medicine where they have gained expertise and skills in communicating with families during their end-of-life decision making process. In addition, they receive extensive training, ongoing, so that they have a better understanding of grief, the grief process and being able to shepherd families through this difficult time. This ongoing program of training helps improve the communication skills and better serves these families in crisis.

This training is not only essential, it is really required by federal oversight, that we have trained and qualified staff to interact with families at this most precious time. House Bill 30 further improves the sensitive process by aligning the hierarchy for donation decision making with the hierarchy the hospital used for end-of-life care. Right now, there's a disconnect between who can donate, who can say yes to donation and who directs a patient's care. This hierarchy in House Bill 30 improves that situation.

And it's important that we get this right. Families will only have, typically, one opportunity to donate. This is rare. And so at that time, we have to make sure that each family is treated with the most upmost respect, care and sensitivity for their family.

Passing House Bill 30 will ensure that families are given that best opportunity and that we can create a lasting

legacy for the loved one. Next slide, Howard.

Following consent from the family, the coordinator will now seek approval from the coroner and the medical examiner for the donation process to continue. It's important to recognize, as stated in the National Association of Medical Examiner's Bulletin, that organ donation doesn't preclude a full autopsy, it doesn't preclude a full investigation, it simply means that the autopsy and investigation has to be done in a slightly different manner.

Nothing in this Bill removes the medical examiner or coroner's jurisdiction or the ability to decline a specific organ for transplant if it's needed in their investigation. House Bill 30 ensures that the decision for donation, however, is made under demonstrated best practices, for a forensic investigation in collaboration with the organ donation organizations. These things are not mutually exclusive, and organs are not needlessly needed to be declined due to a lack of information or about fear. We can do better than that as Pennsylvanians.

Currently in New Jersey, a similar legislative Bill has existed for 20 years, and because of that, not one organ has been buried needlessly, and has never interfered with a criminal prosecution.

We know that there's significant variation in coroner practice regarding donations from county to county, and

as Howard said, election to election. This House Bill 30 will help memorialize some of the best practices.

We know over the last ten years in our area, over 30 cases resulting in the needless denial of over 240 organs has occurred. We know in the last 30 days, 16 organs were buried unnecessarily. This is significant. As Howard stated, children die at a rate of four times those of adults on the waiting list. We can do something about this, and I would urge that you would pass House Bill 30.

Next slide. In best practice counties, it is occurring today in Pennsylvania where organ donation and full investigation is a collaborative team effort by the coroner, the medical examiner, the forensic pathologist and law enforcement. We're able to provide a litany of clinical information during the patient's ICU stay and during the operative phase so that everything that they need for a full investigation is corrected and documented. This best practice can and should be adopted in House Bill 30.

Next slide, Howard. Finally, in summary, I would like to join Howard, my colleague, to implore you to pass House Bill 30. I believe it will improve the donation process by aligning family decision hierarchy at the time we're approaching for donation, will standardize the evaluation of a donation process and will incorporate best practices for collaboration between organ procurement organizations and

coroners. Thank you for the opportunity to testify here today, and we'll be happy to answer any of the Committee's questions.

CHAIRMAN CUTLER: Thank you, gentlemen. Before we proceed to questions, I just want to recognize Representative Dean and Benninghoff, who have both joined us in the interim. The question that we were discussing up here, and I'm hoping you gentlemen can shed some light on, is in regards to the tests that are initiated, you know, in order to determine the appropriateness or particularly what organs or tissue you might be interested in, who pays the cost for those?

MR. NATHAN: A hundred percent of those costs are paid by the organ procurement organization.

CHAIRMAN CUTLER: Thank you. Other questions? Chairman? All right. Well, thank you all. I also want to thank you for keeping us on time. I certainly appreciate it. And I'll invite you, if you have any further follow-up questions, please feel free to send any correspondence to the Committee.

MR. NATHAN: Thank you very much. We appreciate it.

CHAIRMAN CUTLER: You're very welcome. Our next panel will be Monica Forte and Elizabeth Wertz Evans. Thank you both for joining us here this morning. You may feel free to start as you wish. And it looks like we have an extra little guy here. Do you want to go ahead and introduce yourself, buddy?

MS. FORTE: Can you reach? Liz and I discussed last night that she would go first.

CHAIRMAN CUTLER: Okay.

MS. FORTE: So ---.

CHAIRMAN CUTLER: Very good.

MS. EVANS: Well, good morning everyone. My name is Liz Wertz Evans, and I would like to thank each of you for being here, Chairman Cutler, and especially Representative Petrarca for introducing this Bill.

I'm actually here as kind of two people. I'm not schizophrenic, but I'm here as a registered nurse, and I'm also the mother of an organ donor. My daughter, Amanda, was an organ, tissue and cornea donor back in 2001. She was 14 years old, and I do have some pictures of her up here.

She was 14 years old when she died. Prior to that, she had multiple disabilities, from the time she was ten weeks old until the age of 14, when she died. And all during her life, we were told that, well, you know, Amanda can't do this, and Amanda can't do that, and she doesn't speak, and she's not able to walk on her own, and she can't eat by herself. But when it came time, and we realized that she was in the hospital, she was in the intensive care unit, and she was pronounced brain dead.

My husband and I were both nurses, and we actually pretty much realized that there was no hope for her, even

before she was officially pronounced brain dead. After that happened, and there were a multitude of tests, one of the things that we talked about was, well, all Amanda's life she wasn't good enough for this to happen, this to happen or this to happen. But when it came to organ donation, she was good enough to donate. And that was incredibly important to us, because we couldn't change Amanda's fate. We knew that she was going to die, and so we couldn't change any of those things, but what we could change is prevent another family from having a child or their loved one die because they were waiting for an organ transplant.

We found out, first off, that Amanda's liver would be going to a 12-year-old little girl. And as soon as we knew that --- again, I have goose bumps even talking about it. As soon as we knew that, we knew that her life had purpose. Even though she wasn't going to be alive anymore, we knew that her life would carry on and give life to others.

So her liver went to a 12-year-old girl. Her right kidney went to a 33-year-old man. Her left kidney, pancreas and bone marrow went to a 36-year-old man. Both of her corneas were given --- well, one each, one to a 79-year-old woman, and one to an 84-year-old woman. And a few years later, her heart valves were also implanted into two different people.

It's kind of hard to explain the feeling that we had related to organ donation, because it really did give us a lot

of comfort. Again --- and I keep saying this, we knew she was going to die and there was nothing we could do about that. But the fact that she --- her life would go on and other people would live because of her was incredibly important to us.

We also knew that Amanda's case was a coroner's case. And we knew that she would need to have an autopsy, and the folks from C.O.R.E. came in, they sat down with us, they explained the donation process. Again, my husband and I were both nurses, but we had really never been --- we've been on one side of explaining organ donation, but we had never been on the side of having to donate our child's organs. So they were incredible in explaining the process to us.

And again, we knew there was going to be an autopsy, and we were a bit concerned, because donating her organs was incredibly important to us. And we felt that --- you guys okay? No passing notes in school. We felt that if we were denied the opportunity to donate her organs, it would be like she died a second time, because we knew that feeling was absolutely horrible and it was incredibly, incredibly important to us that we were able to donate her organs.

One of the other things that we were able to do after several years was to meet the recipient of Amanda's organs. Well, actually, not all of them. Meet the recipient --- meet the person who received Amanda's liver. Her name is Dayna, D-A-Y-N-A, and C.O.R.E. was just amazing in connecting

us. We had been communicating anonymously for a few years, and then she decided she wanted to meet us in person. So we met at C.O.R.E.'s office.

And it's really hard to explain the feeling as a parent, knowing that this vibrant young lady, who was now 24 years old, sitting in front of you, the only reason that she was alive was because we made that decision to donate Amanda's organs. Again, more goose bumps, and it's not cold in here.

But when I hugged her for the very first time, it was like I felt like Amanda. And my son had said to me, mom, don't weird her out, you know, it's not Amanda in there. But there was just this feeling of peace, knowing that Dayna was alive because we made this unselfish decision to donate our child's organs.

So I would ask each one of you to please consider what this means to not only to the recipient, because it obviously means a great deal, because they're going to have a second chance at life, but also how important it is to those of us who are donors --- well, actually, I guess I'm considered a donor parent, but how important it is to the family of the person who would be donating those organs. It really is --- again, you can't change the death, but I know, especially, in our case it gave us incredible comfort to know that we were going to make a difference, and that Amanda's life was purposeful and that she was making a difference through these

other donations.

So I would ask you to please --- I would challenge you to please pass this Bill. It's not only important, as I said --- and I'm repeating this just for emphasis. It's not only important to the recipient, but it's also incredibly important to those of us who have had to make that lifesaving decision.

MS. FORTE: Good morning, Honorable Representatives and distinguished guests. We thank you for this opportunity to share our journey with you. We would like to share something that we recorded with Gift of Life, since we were part of Gift of Life about two years ago. Tony is the poster child with Gift of Life in our state. And we've recorded a 30-bit commercial as to why the need is so great for us. Let me see if I can do this the right way here. I don't know, did I do it right?

(Recording played).

MS. FORTE: I am Monica Forte, and this is our youngest son, Tony Forte. My husband and our other son is in the audience. We are from Lancaster County, Lancaster, Pennsylvania.

Tony was just discharged last Wednesday from the Children's Hospital of Pittsburgh where that transplant will be taking place. He had undergone major abdominal surgery on April the 24th and was in surgery for about nine hours to help

aid him while we're waiting for transplant. So as a mom, you boast about your children, it's honorable to see him here. We were trying to do a news feed from the UPMC Children's Hospital of Pittsburgh if we were not able to make that. We're here today, but we're very honored to be here and be a part of this to share with you.

As Liz had mentioned, you know, it's very honorable for her, to have this Bill pass, because she's a donor family, and because we are a transplant family waiting, it's going to take somebody like her to make that decision for Tony's life. In the clip that you just viewed, my son says, well, it really does suck. And I'm here today to tell you why that does, on not only Tony's life, but on 204 children that are waiting in the State of Pennsylvania currently right now for organ donation.

Imagine you as a child, or your children, your own children, not being able to attempt a sense of normalcy after being diagnosed with a chronicle life threatening or a terminal illness. For Tony, he's never been able to attend preschool or school, never been able to have any sleep overs due to medical necessities that he has to wear. Never had been able to swim in the summer. He's never been able to be bathed in a bathtub or take a shower because of the medical necessities that he has. He has to be sponge bathed. And to never be able to eat a full meal any time from the time that he was six days old

until he gets this transplant without becoming sick.

For many children like Tony living in and out of Children's Hospitals wearing medical devices that, for the meantime, is keeping them alive and not having the ability to maintain a normal quality of life would suck for anybody. But for Tony's life, normalcy wasn't meant to be. By the sixth day of life, both myself and my husband knew that something was terribly wrong with Tony. And we needed answers, and we needed fast answers as to what was going on with him.

He was born on Father's Day that year, June 2005, so I gave my husband a gift that I'll never be able to give, a son on Father's Day, and never be able to attain that, that height of level. But within hours of his arrival by ambulance at the Penn State Childrens Hospital in Hershey, Tony was under the guidance of the head of department of pediatric surgery, under the guidance of Dr. Robert E. Cilley.

And he was whisked away for five hours. We had no idea at the time what was ailing Tony. After he came out of surgery in five hours, we were told that the doctors believed that he had a condition of his intestines known as total colonic Hirschsprung's disease. And for us, we never knew what that word meant. We didn't have anybody in our family genetically have that disease, so this was a shock and awe for both of us at that time.

But one thing that Dr. Cilley also mentioned was

that it was going to take a lot of love to care for Tony, and that just wasn't the hugs and kisses that a normal parent with a normal baby boy or daughter has. And what that meant was it required us to learn every aspect of Tony's care in a short amount of time, and we were told that if we weren't able to do that care, that he would have to go to foster care. So we had to really get ourselves in gear in caring for Tony medically, and we never had a medical background. So basically, we had to become R.N.s overnight.

And that meant we had to make him priority along with our other two healthy children, who were only four and two at that time. So not only did we have Tony, but we had a young family back in Lancaster, and we had to make that shift as to, you know, do double trips back and forth to Hershey, take turns taking care of him. We never left him alone in the hospital. He couldn't call a nurse's bell. He couldn't even tell what the nurse's, you know, what was wrong with him. He was just an infant to a toddler.

And so in that time frame, we had to give up our means of employment. Tony required both of us taking turns, like we said. Our boys actually had to give up being schooled in the public school and Catholic school, and we actually had to start homeschooling them to care for Tony and to keep the germ level down, once we knew that he was going to be listed for transplant.

I learned all his IV induced nutritional care. My husband learned all of his ostomy care, and we estimated that probably about 100-plus admissions Tony had in short nine years, between the Penn State Childrens Hospital and also the UPMC Childrens Hospital of Pittsburgh.

Four years ago it was decided that to improve Tony's quality of life and give him a better chance of --- one would benefit from a multivisceral transplant, which like we stated, and he mentioned, he's going to be going for a stomach, small and large intestine and liver transplant.

His surgery will take place at the Childrens Hospital of Pittsburgh, UPMC, and only four Childrens Hospitals in the United States perform this vital or lifesaving transplant. So we are very fortunate and blessed that we have not only the Pittsburgh Hospital of the Childrens Hospital there, but we also have the Penn State Childrens Hospital, and even CHOP. We have three great Childrens Hospitals in our state. And some states don't even have one, and they come from miles away to come to our hospitals here.

Of the children that are waiting, there's 200, like I said, plus children waiting today for lifesaving organs, but we are waiting, like we said with Liz, the unconditional love of parents through the unbearable loss and grief of their child at that time making the same decision that we're trying to ask them to make, and will you give us the life of your child to

save Tony and these other children.

This vital Bill is very dear and it holds a very personal stake with us since we got involved with Gift of Life almost two years ago. Because we go to the Penn State Childrens Hospital on a monthly basis, back then, the Gift of Life office has a satellite office on Fishburn Road. And my eldest son at the time was 11, and he decided that he wanted to go into the office and visit, and that's where we met Wendy Johnson of Gift of Life.

And we fundraise on behalf of Tony. My 13-year-old son's not here today. He's back at the hotel, but my son Dominic is in the back. And to date, they have raised over $200,000 in a special needs trust that's for him. When we go to fundraisers, when we setup fundraisers, we're always promoting Gift of Life and what that means to us. And we always have this question as to why is it taking so long to save Tony's life. And it's because there's not enough children that are becoming pediatric donors in our state. And like Howard Nathan, CEO of Gift of Life stated, that there's a four time greater risk of children dying waiting for that lifesaving organ, because there's not enough pediatric donors.

This bill will encourage and strengthen that bill and that awareness of education for us as families to talk to other pediatric families and to get their children, who are healthy, listed to become organ donors.

You know, we don't have time --- we never had time. When Tony got listed for transplant, our time went right out the window. We have to live by that telephone every single day, every single minute, because that time can be that we only have six hours to get Tony out to the UPMC Childrens Hospital of Pittsburgh waiting for a life. Now, at that time, although we get that call, it might be a false alarm, and it might be that that parent might say no. And so we have to go through that process again.

Right now Tony is at --- from a status two, he's down to a status 1B since his last surgery just two weeks ago. Some of his organs are showing some signs of damage due to the IV nutrition that he's wearing. So he doesn't have that much time. And right now, they're just aiding time for him and getting him to where he needs to be, so when we get that call for transplant, he will survive.

Thinking about it and becoming an organ donor doesn't save lives, and the lives like Tony's and countless children and adults waiting. But something about it today will do, and that's both you guys passing this Bill and getting it out of the Appropriations Committee and putting your name on it and getting it done.

We have in our local community talked to Senator Mike Brubaker. We talked to Senator Lloyd Smucker. State Representative Steven Mentzer. I know these men very

personally. I was in local politics, even when Tony was kind of ill and trying to focus my sense of --- you know, some of the medical stuff, I did become very active in local politics, so I know these gentlemen very well, and they're very distinguished men. And they all signed that bill after hearing Tony's story.

To think that we can go to more schools, teaching hospitals, nursing schools, medical professionals with the education and sharing our personal stories and awareness programs among the residents of the State of Pennsylvania, will ensure that everyone, including these 204 children will have a second chance.

I want to share something real brief before we end our testimony. Tony had a dream of like that of a fictional character of Pinocchio. And I never made that relation of that character until we were in the Penn State Childrens Hospital. He was three years old and a nurse from Child Life brought some DVDs for us to watch. And if you can imagine children as a toddler and an infant, they're always in a caged crib so that it protects them from falling out of the hospital bed. And it's kind of undaring to see that, you know. They look like a caged little animal. But Tony braved through it. And as we were watching Pinocchio, Pinocchio started dancing around and started singing I've got no strings. And Tony asked, mommy, I want to be just like him.

Tony pointed to the nurse and said someday I'm going to be like him, I don't want these strings. For Tony to become a real boy and free of the strings, that will take the transplant. And children and adults waiting will have their time. But they don't have any time to wait any longer. So I thank you, and I hope that you pass this Bill.

MS. EVANS: We'll be happy to take any questions if any of you have questions for us.

CHAIRMAN CALTAGIRONE: I just have to share something with you all and the Committee. Several years back I was doing door-to-door work in North Reading, and this mother said come on inside, Tom, I want to show you my baby. And I go whoa, wait a minute. And then it dawned on me. A couple years prior to that, I was doing door-to-door work, as we all do, and at the time they were saying they needed blood over at the Reading Hospital, so I went over and gave a pint of blood.

And while I was waiting to give the blood, there was a young girl there, about 12 or 13, her dad, and the mother who had just given birth, and they were saying you got to give this blood, daddy can't, mommy can't, and I'm sitting there in the waiting room listening, and I'm thinking --- and I'm listening to this, and they say my type of blood that was needed. So I'm going to give a pint anyway, so I say what the heck.

So I went over and I said I'll give the baby of pint of my blood. Well, wouldn't you know, a few years --- and I'm

looking at Tony, and I'm thinking of that. He was a young little boy --- a baby boy, and they gave my blood to that little baby, you know. Now, the baby was maybe a couple years old at the time, and I made the decision at that time also, I'm going to be an organ donor, because if I can help somebody else, why not?

And I hear these stories, and it's heart wrenching. You know, looking at the young man there, I mean, he needs a full life. We need to help.

MS. EVANS: And he can have a full life with a transplant.

MS. FORTE: Absolutely. Yeah, he'll be able to eat a full meal, he'll be able to go to school and become a normal boy, and that's what we need for him.

CHAIRMAN CALTAGIRONE: Thank you both for sharing. I certainly appreciate it. Tony, you're certainly a brave young man, so good luck.

CHAIRMAN CUTLER: Before they leave, any questions from anybody? I didn't see any motioning, so I want to thank you both for your testimony. I also want to recognize we've been joined by Representative Hackett and Representative Regan both. Thank you.

We'll go ahead and invite the next panel up, which is Richard Connell and Sister Clare Schiefer. If you both would join us? Thank you.

ATTORNEY CONNELL: Good morning, Mr. Chairman. Representative Caltagirone, members of the subcommittee and other distinguished members of the House. I am Richard Connell, a partner with the Harrisburg Law Firm of Bell, Murren & Connell, which serves as legal counsel to the Pennsylvania Catholic Conference and the Pennsylvania Catholic Health Association. With me is Sister Clare Christi Schiefer, who is a member of the PCC staff, and is President of PCHA.

For your information, Sister Clare, in the past, served as a member of the Department of Health Advisory Committee on organ and tissue donation during the term of former Secretary of Health Dr. Mueller.

For background information, PCC is the public affairs arm of the Catholic Bishops of Pennsylvania, which represents the eight Latin Rite Dioceses and the two Byzantine Rite Catholic Dioceses. And the Pennsylvania Catholic Health Association is a statewide organization composed of healthcare facilities and other individuals and groups which promotes the integrated Catholic Health Ministry in Pennsylvania.

And before presenting testimony, I note that our remarks are principally directed to Senate Bill 850. And while this hearing is about House Bill 30, Sister Clare and I learned during a recent meeting with Representative Petrarca that House Bill 30 is likely to be changed so that it will be very much like the current printer's number of Senate Bill 850.

That original version of Senate Bill 850 had been the subject of comments by PCC in June of 2013, which were shared with a Greg Warner, who was on Senator Greenleaf's staff. Thereafter, Sister Clare and I met with representatives of organ procurement organizations and had a healthy discussion about issues that had been identified.

The Judiciary Committee of the Senate on November 19th amended the original printers number. And we have submitted another memorandum discussing concerns and observations about the current printer's number, and those are set forth in attachment B to the testimony, which has been provided today.

Organ donation is, in Catholic law, tradition based upon informed consent, which is the stipulation that an organ donor must explicitly consent to the donation prior to organ donation or organ procurement, and informed consent is a necessary component of the church's teaching on the morality of organ donation and transplantation for two reasons.

First, informed consent affirms and protects the intrinsic dignity and inviolability of the human person. Next, informed consent respects the essential formality of the donated organ as a gift that one person gives to another.

Father Austriaco, who wrote an article for the National Catholic Bioethics Quarterly, is quoted here at length, because he so well captured the church's position. He

noted, since the time of Pope Pius XII, the Catholic church has explicitly supported the procurement of organs. For the Catholic law tradition, organ donation is justified by the principle of charity. The person who donates an organ to a patient is making a genuine act of sacrifice modeled after the Lord's sacrifice of himself on the cross. Organ donation is an act of self gift of the human person.

As recently Canonized John Paul, II emphasized, every organ transplant has its source in a decision of great ethical value, the decision to offer without reward a part of another person. Here precisely why is the nobility of the gesture. A gesture, which is a genuine act of love.

In the catechism of the Catholic church teaches, organ donation upon death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity. To understand the church's view of organ donation, it's also important to know that the ethical and religious directives for Catholic health services issued by the U.S. Conference of Catholic Bishops provide that Catholic healthcare institutions should encourage and provide the means whereby those who wish to do so, may arrange for the donation of their organs and bodily tissue for ethically legitimate purposes, so that they need be used for donation and research after death.

The Catholic church of Pennsylvania is no stranger to the issue of organ donation. In 1995, the Pennsylvania

Conference on Interchurch Cooperation, which is a statewide ecumenical organization, representing Anglican, Orthodox, Protestant and Roman Catholic church bodies in Pennsylvania, joined in urging the people of the Commonwealth to share the gift of life through donations of organs, tissues and blood.

These church groups urged the members of the christian community to lead the way by talking to people in their families, congregations and communities about the possibility of donating organs and tissues. They asked pastors and other church leaders to encourage it in their parishes and congregations.

While PCC and PCHA were considering this legislation, we've had the opportunity to turn to the PCHA Board, which includes hospital CEOs, long-term care facility representatives and the lead emphasis from a major national Catholic healthcare system. These members have provided wonderful insight into the organ procurement process and have affirmed the especially laudable informed consent decisions to donate organs.

In addition, PCC and PCHA have turned to Dr. Marie Hilliard, the Director of Bioethics and Public Policy at the National Catholic Bioethics Center in Philadelphia. Dr. Hilliard's comments about the subject legislation are incorporated below in the testimony, which focuses on some of the areas noted in attachments A and B to our testimony today,

which are the memoranda to which I've previously referred.

The focus of testimony today relates primarily to the list of those authorized to consent to an anatomical gift. How that list is used, whether presumed consent is in effect created, the effectiveness of the revocation of gift and the possible invocation of foreign laws. To the extent that the issues set forth in attachment B are not specifically discussed here today, please know that those concerns still remain.

The bill provides the coroners or medical examiners, wardens or correctional facilities where a decedent is incarcerated, an administrator of a social service agency having a relationship with a decedent, a person that exhibited special care and concern for the decedent or a hospital administrator can donate all or in part of a decedent's body. While clearly intending to expand the number of potential organs, that groups seems unlikely to produce any type of informed consent. Instead by conferring the power to make gifts to such individuals, there is, in our view, the creation of presumed consent.

Such persons with authority may simply see donation as a duty requiring little thought and reflection. But for the decedent from who the organs would be taken, he or she will have no advocate and no balance. The donors could include the poorest of the poor or the most outcast. By creating this authority, the state, in effect, moves away from informed

consent. Some concern also arises as it relates to limited liability for a person under Section 8616 of the legislation.

Current law already provides that there is limited immunity for act in accordance with the anatomical gift laws of another country. But the status of the anatomical gift laws has changed significantly over the years. In Europe, for example, the standard now is presumed consent. Does this part of the legislature then mean that immunity is conferred even if the person acts in a manner inconsistent with carefully crafted Pennsylvania law? That simply does not seem desirable.

Another area to consider is that which deals with the effectiveness of a revocation. A revocation takes effect, for example, in the Bill before a decision has been made to remove an organ and before evasive procedures have begun for the recipients. There is a balancing here. But if an attempt is made to revoke, it should be observed that a simple incision can be reversed. As to the recipient, who it is noted, has much at stake and has been prepared for a transplant, if the invasive procedure, which is discussed in the Bill is a venous line, should that act alone preclude an effective revocation by a family member?

Dr. Hilliard, who I mentioned earlier, noted a concern about the procedure to be followed by hospitals, which would require notification of the organ procurement organization that death is imminent. She advised us that the

National Catholic Bioethics Center had secured an agreement by the Organ Procurement and Transplantation Network in its non-heartbeating death protocol, but none of the procedure can occur until the family has decided to remove life support. Such a step or clarification seems advisable here as well.

Under the Bill, hospitals are precluded from withdrawing or withholding measures necessary to maintain medical suitability. Dr. Hilliard further noted in her review that with respect to one of the sections in the Bill the National Catholic Bioethics Center had negotiated with and achieved agreed upon language with the National Conference of Commissioners on uniform state laws in November of 2009. That language was set forth in attachment C to the testimony today.

Please note that careful attention to the concerns raised and the issues identified is appreciated. As stated earlier, the Catholic church has long advocated for and encouraged organ donation. That advocacy is based upon a donative spirit, informed consent and respect for the dignity of the person. These bases are the foundation upon which the Catholic church evaluates such well-intended legislation.

On behalf of the Pennsylvania Catholic Health Association and the Pennsylvania Catholic Conference, we thank you for your attentiveness.

CHAIRMAN CUTLER: Thank you very much. Any questions? All right. Actually, Representative Saccone has a

question, if that's okay, Attorney Connell?

REPRESENTATIVE SACCONE: This may be a clarification, but you know, I listened to some of these arguments before, and I mean, we have some compelling testimony here before you about their emotional testimony, about the long waits and how organ donation will save lives, and who wouldn't want to help somebody like little Tony? I mean, there's nobody that I know of that wouldn't want to help.

It comes down to some of the things you've raised in your testimony, which you didn't talk about, but it's in your testimony, about --- there's a couple of main arguments that maybe you should comment on. One of the key arguments of those proponents of this is to accept brain death as death. And not everybody agrees that brain death is death. If you have a functioning heart that's pumping blood through your body, many people have survived brain death, or so called brain death. And so that's one question.

And the other question is another thing I'd like you to comment on, is you mentioned in your testimony is that when you --- when we start harvesting organs and organs become a big business as it has become, then the definition of life itself, especially when you are on the precipice of death, becomes a cost benefit analysis. Does it cost more to keep you alive than you're worth, if you're dead, if you harvest those organs?

And you said in your testimony that at some point if

you have all of these people that can authorize a donation, that then your organs are --- no longer really can be classified as a donation, they're being compelled by somebody that's not you to be given away. Do you want to elaborate on any of that?

ATTORNEY CONNELL:

With respect to your first question about brain death and its acceptability, Sister Clare, who is the nurse between the two of us here, can clarify on this, but those standards have been accepted in the healthcare community. It is an accepted and reasonable standard to follow. There are differing criteria from time to time over some timely issues, but brain death is not disputed in the Catholic tradition.

As to the second question, I don't know that our focus is ever on that this might become a business opportunity, and that there is a denial of the worth of life for good and ultraistic reasons. But the focus of our testimony is simply that this should be a gift, and there should be people who have an interest and have a closeness, and that's where there's some concern, some reluctance, some hesitancy to extend the list too far. Even though we acknowledge that good might be done, it may go just a step too far.

REPRESENTATIVE SACCONE: Thank you for your testimony.

CHAIRMAN CUTLER: Attorney Connell, actually, I have

a follow-up in that regard. Hearing from the folks, I believe it was the Gift of Life executives had testified that there are multiple other states, and I certainly don't expect an answer now, but I would be curious what the Catholic Conference has done in those other states where they have this. Have they found agreed upon language where, you know, the list of individuals had been meted down, or conversely if it's a social worker and some of the other folks who are on that list, is there an active attempt to ask them about their desires going forward?

I have to think that we're not reinventing the wheel here to that extent, and I don't know if you had any knowledge.

ATTORNEY CONNELL: I don't particularly, but we'll certainly inquire of the other Catholic conferences what they've done. Certainly, Dr. Hilliard is very well informed on this issue and can help us in that regard.

CHAIRMAN CUTLER: Thank you very much. Counsel Dalton would like to ask a question, if that's okay?

ATTORNEY DALTON: Thank you so much. It's so nice to see you again, Sister Clare. I have a question, and I have to admit I'm not a medical person. If I knew anything about math or science, I would have gone to medical school and not law school. So my understanding, after reading some of the information on the website of the Uniform Law Commission is that there's a change, again, with respect to the brand ---

with respect to death, and this idea about cardiac deaths. I was hoping I could speak to that and the change and why that's important with respect to this issue.

SISTER SCHIEFER: I'm pleased that you answered --- asked that question, because actually, we were very early after there was publication about the non-heart beating organ donation or cardiac --- after cardiac death organ donation, and we actually encouraged our hospitals to participate, and we send out guidelines to them, so that they would be able to do it in an appropriate manner that was acceptable to the church.

CHAIRMAN CUTLER: Any further questions? Thank you both for your time this morning.

ATTORNEY CONNELL: Thank you.

CHAIRMAN CUTLER: With that, we'll invite the next panel up. Susan Shanaman, David Freed and Ellen Kramer, and you all may begin when you feel appropriate in whatever order you would prefer. I'll defer to the three of you as to the order you wish to proceed in.

ATTORNEY FREED: Good morning, all. Thank you for this opportunity. And it's always a real pleasure to be here in a room with so many good friends. Chairman, it's always a pleasure to see you in your element.

I am David Freed, District Attorney in Cumberland County, and until the middle of July, President of the Pennsylvania District Attorney's Association. We've had

significant discussions about the bills at issue here within our organization. And I'm happy to say that about two months ago in March in Pittsburgh a number of members of leadership of our organization and folks from C.O.R.E. and Gift of Life got together and had what I think we all consider to be a very productive meeting.

There's been some information shared after that, and we are confident in our ability to work together with those groups to try to deal with some of the concerns that we have that I'll be talking about today. So I say that by way of preamble to let you know that we've been working outside of this room. We don't see this as a battle so much as an opportunity to work together to try to get the best Bill we can. And most of you on this Committee have seen that sort of process take place with any number of Bills, where we work together to try to come up with language that is the most acceptable to all groups. So on behalf of the Association, that's some background.

And I want to be clear from the outset, we are supporters of organ donation. I'm an organ donor. And we know that organ donation saves lives. I can tell you three stories from the last several months in situations that I've confronted in my role as District Attorney in Cumberland County where we've had discussions among the coroners in Dauphin County, Cumberland County and the folks from Gift of Life. And we've

been able to work out accommodations that allowed organs to be harvested and also preserved evidence for a criminal case.

The reason that Dauphin County is involved is that so many of our traumatic cases end up at Hershey. And similarly, in other parts of the Commonwealth, a lot of the cases, especially those involving children, end up either at CHOP in Philadelphia or Children's in Pittsburgh. And I say that as an introduction to one of the issues that we have some concerns about.

But we have stories from all over the Commonwealth of opportunities that we have and seized to work together with our coroners and the organ donation folks to make sure that we can preserve both goals. And that's what we'd like to be able to do. And we'd like to be able to preserve the opportunity to have those discussions and make sure we can reach those accommodations.

Having said that, I'm mindful that we all took an oath to pursue justice, hold offenders accountable and protect the public. And those goals are entirely dependent on the integrity of criminal investigations. We can't do justice in a case for a victim if the underlying investigation is incomplete or compromised. In this area of futuristic criminal justice TV shows, juries have high, sometimes unrealistic, expectations of criminal investigations.

I also believe that we have to be mindful of victim

sensitivity and ensure that the worthy goal of organ donation doesn't get in the way of being sensitive to the families of victims, who have just learned their loved one has died or will die.

I want to discuss several specific concerns that we have. One is guidance on jurisdictional issues. And I've presaged that by talking about the cases that start in one county and end up in another. And often that's Allegheny, Dauphin and Philadelphia, because of the incredible medical facilities that we have to treat people in those jurisdictions. When a crime occurs in one jurisdiction, the victim's taken to a hospital in another county and death occurs, who from the law enforcement and investigative perspective should decide whether organ procurement does or does not harm the criminal case?

It's not a theoretical issue. It happened towards the tail end of last year in a case from Clearfield County where the child who was taken to Allegheny County and organ donation became an issue. I got involved personally in that case at the behest of the District Attorney in Clearfield County, Bill Shaw. We were able to get UPMC involved. And ultimately there was a hearing that took place, and there really wasn't a process or a precedent. The hearing was on the telephone. It was an emergency hearing. We had some concerns about the way that it went. I sent a letter, I know, to leadership, I don't know if it got to everybody, about that

situation and decrying some of the things that happened.

One of the good things that came out of that situation, however, was that I received a call and a visit from an attorney named Paul Vey from Allegheny County, who represents C.O.R.E., actually drove to Carlisle to sit in my office with me. And that was the genesis of the meeting that we had a couple months later in Pittsburgh, to get the groups together. Having said that, we worked together and had some good meetings.

I want to lay out the issue just so that you have it in front of you to consider. The baby was airlifted to UPMC and declared brain dead. There were two suspects, the father and the stepmother. Now, giving her pending death, C.O.R.E., the local organ procurement organization, sought consent to have the organs harvested. The father agreed. The problem there was that the father was a suspect in the abuse of the child. So District Attorney Shaw objected on two grounds. He believed that harvesting would compromise the investigation and, of course, that the consent had been given by the father, who was a suspect.

C.O.R.E., I think, reasonably then sought consent from another. That would make sense, most of the time, however, the mother in this case had serious drug issues, hadn't seen the baby for the proceeding eight months. In fact, Children and Youth Services were involved in Clearfield County

with this child. None of this necessarily known to C.O.R.E. or the courts in Allegheny County. I'm just pointing out the issues that come up in cases like this.

Ultimately, there were competing court orders. There was an order from Clearfield County vesting fiscal custody of the child in Children's Services from Clearfield County. There there was an order from Allegheny County from the judge, relying on the opinion of Dr. Carl Williams, who was also at our meeting in Pittsburgh, you know, who's eminent in his field, indicating that he believed the organ harvesting could be done and still preserve the integrity of the investigation.

We understand completely why a judge, based on the evidence that was presented to him, made that ruling. It still doesn't take care of the issue that the voice of the DA and the investigators in Clearfield County wasn't necessarily given the consideration it was due. We have concerns about the due process rights afforded to the victim. And because the potential criminal matter belonged in Clearfield County, that Clearfield County should have had the final say.

Neither House Bill 30 or the companion legislation addresses this situation. We don't believe this is an insurmountable issue, but we believe it's an important issue that we need to discuss as we're developing language that we can all agree on. This is a scenario likely to occur at CHOP,

at Hershey, at Children's especially. It's a highly fact specific question. I don't know that it will be easy for us to come up with legislative language to deal with it, but I believe that we need to try to do that and work together in order to make that happen.

We believe law enforcement personnel in the county where the crime took place should have final determination. Coroners and medical examiners in the county where the body ends up don't have the same interest. And we had a very productive conversation with Dr. Williams about it, and in some senses agreed to disagree. But that's an issue of concern to, I think, both coroners and to the DAs as it relates to the integrity of investigations.

We also have some practical concerns regarding the process for denying organ harvesting. As currently drafted, the legislation can be interpreted to effectively put the body in the hands of the OPO and shift the burden then to the coroner or the medical examiner to object. We had some very productive conversations around this issue in our meeting. And we don't believe --- or I certainly don't believe based on the feedback that we got at the meeting that that is what the organ procurement organizations intended, to essentially take custody and then force law enforcement to object. So we believe that that language needs to be addressed, or that situation needs to be addressed in the Bill.

It's not clear that that's the intent in the Bill, and we think that clarifying language should be drafted. We understand that most organ harvesting takes place in hospitals, OPOs, however, are equipped with sterile surgical rooms to do it. Harvesting could take place at their offices. It's difficult from the practical perspective and also in terms of keeping track of location of the body, and from an evidentiary perspective, adds another destination, potential chain of custody issues for us before the autopsy finally takes place.

Where would we want harvesting to begin if we know from the outset that harvesting would compromise an investigation? It may seem far-fetched or something out of a movie; however, we think that we can deal with that issue in the drafting of this legislation.

OPOs have shared their protocols with us following the meeting. I'm impressed by that. I was impressed by my colleagues from the OPOs at the meeting. I'm impressed by their protocols. The kind of situation I have discussed couldn't happen, but protocols can change and they're not binding. And we don't know who may be representing the interested parties a decade from now when this becomes an issue. During our meeting, we all seemed amenable to attempting to address this situation.

We would suggest also the Bill provide some provisions for administrative oversight, whether that's

Department of State or Department of Health that would help us to track and resolve disputes between OPOs and county medical examiners and coroners. It would also allow further discussions, updates and sharing of protocols among the stakeholders. Oversight could and should diminish any unintended problems going forward.

Finally, I want you to understand why we've been so tuned in on this legislation and where some of us lack comfort. Failure or not, we've heard stories about complaints in the manner in which victims families are counseled about potential organ donations.

And we understand, certainly, that the best of intentions sometimes may not be interpreted that way. I've certainly had that experience as a District Attorney, and I know my good colleagues who've been in law enforcement have had the experience that when a coroner or we are dealing with a victim's family who suffered a traumatic event --- just had this situation at three o'clock this past Saturday morning. What they are told doesn't necessarily take, and then when you hear it described the next day, you'll get a call saying, oh, that coroner was awful to me. And then when you hash it out, it has to do more with the situation that was going on than the words that were said.

So I'm confident that most of the situations have been described to us have to do with that sort of situation.

But we need to always understand that there are certainly the sides of the needing recipients of the organs, and we also have to understand the victims in this case. You know, I have a son who's 12 years old who's a Type I diabetic, diagnosed when he was five years old. You know, we tell him all the time, by the time that he's an adult, science will probably have advanced to the point where he can get a pancreas transplant and he won't have to wear a pump or take shots. So this is personal to me as well, because I'm hoping that we can get there.

We believe the Bill has laudable objectives. We're firmly committed to working with other stakeholders to get this done. We all want to save lives. We in law enforcement have to always be mindful that we need to hold offenders accountable as well. I thank you for the opportunity to be here today. I'll have to turn it over to Susan, and then we'll go to Ellen, and then be happy to take questions.

MS. SHANAMAN: Chairman Counsel Caltagirone, Chairman Cutler, members of the Committee. My name is Susan Shanaman, and I'm here representing the coroners, Pennsylvania State Coroners Association.

I want to thank you for allowing me to be present today to discuss what the coroners believe, generally, is a bigger goal where you have organ donation. They support life, they support organ donation. I think maybe if you looked at it, it's probably a measure of the fact that what they deal

with on a daily basis is death.

They're the ones that get the calls at 2:00 in the morning and have to go out. And they see death every day. So do they support life, yes. Do they support organ donation, yes. But they believe that the Board goes a little too far in terms of taking away the jurisdiction and the ability of the coroners to investigate those deaths.

As you know, the coroner has existed in Pennsylvania since William Penn in 1693, put it in the forced frame of government for Pennsylvania, and that was the establishment of the Office of Coroner. They are elected officials, basically, just like you. And they are there to serve their constituency. They have three primary goals, and that is for the --- all deaths, which are essentially of a violent nature and other than a natural death, they are responsible and must according to law investigate those deaths. They must determine a cause of manner of death. They must --- in determining that, one of the primary tools that they are able to use is that of an autopsy.

They work with the Dave Freeds of this world, as he is in various counties. And they believe that they are also helping to save lives, by bringing persons to justice, and therefore, preventing them from killing again. They believe they save lives because during an autopsy, they may find that a genetic illness exists, and they can tell the families about

that, and that can help also in saving lives.

The coroners are not in opposition to the harvesting of organs. Matter of fact, I did quick research of the recent report that is filed with the federal government. And the denial of organs by coroners amounts to one half of one one-thousandths of one percent. Where they deny organs being taken is where they believe it will interfere with an investigation and where the family says no.

We're a pluralistic society. Even where you may decide that you would like to donate your corneas, you may also feel that you don't want to donate skin. This Bill will change that. Once that you have said that you're a donor, you are donating anything, everything, the way the Bill reads, whether that's what your belief would be or not, and it's being done for transplantation, therapy, education and research. The last two, in particular, being --- it could be characterized as medical experimentation, and it is something that even the federal government says, by regulation, must be done with informed consent. We are concerned that much is being lost in terms of informed consent.

Now, just in case you would think, well, I'm just saying that this is happening to coroners here, and if we just pass the reg, I think you said 45 other states have already passed, then everything will be fine. I can tell you that --- and I'll refer to it in my testimony, and if you want a copy of

the studies, I'm more than happy to send it to the Chairman for its circulation among you. I can tell you that most recently, I think it was 2010, in the Journal of American Pathology that a Houston medical examiner wrote an article about how the harvesting had prevented him --- in the cases of five children and one female adult prevented him from determining a cause and manner of death.

In the case of Baby Sophia, which Dave Freed referenced to, I believe that cause of death is listed as pending. The only thing I can say is I don't think that two-year-old little girl caused her own death. But will anybody ever be brought to justice for it? I think that's questionable.

So you've got Texas as one example, that's indicating there's an issue here. I know the Maine report was mentioned. That report expired, I think, last year because their policies always expire at the end of five years, and they are working on a new report.

In addition, Michigan, in March, there's a situation with a little boy, I think six years old, and he was found with burns over 49 percent of his body. He was brutally traumatized, and his parents were arrested for first degree child abuse and homicide in the case of the father. And when it came to --- and the police, I felt, were gracious. They --- upon request of the mother, she wanted to see her child one

last time.

At that point, the Michigan Gift of Life asked for permission for donation. The police went to the courts and got an order saying no donation, because the M.E. needed to do an autopsy. The Gift of Life of Michigan is now suing the M.E., saying that he has violated the Uniform Anatomical Gift Act by not giving them the body first. That's the issue for the coroner. Can we do the job you have asked us to do, which is to investigate, to help police, to help other law enforcement, to help the DAs to bring people to justice who really need to be brought to justice?

There also is --- in the Bill, it states that the OPOs will be gracious enough once they have the body, that the coroner is allowed to watch while they harvest. And that is to take the place of an autopsy. It's not how autopsies are done. Now, just case any of you are thinking, are all the coroners out there just cutting bodies open? What is their qualifications for it? No, they're not. Some are, as in Dr. Gulino's case, who you will hear from, medical doctors, same with Dr. Carl Williams, same with Dr. Hellman in Delaware County. Those three are medical examiners.

What the coroners do is they rely upon forensic pathologists to do the autopsies. These are people who are scientifically trained to look for evidence. Now, in a couple instances, the coroners have asked one of the OPOs --- okay, we

will take the photographs, send us a copy. And the photographs they get, which is what the law --- what House Bill 30 says, the photographs they get are maybe taken from a cell phone. They have no depth, they have no measurement, they are not scientifically qualified. You can't take that and use that as evidence before a court.

The coroners have, in some instances, asked for tubes of blood. That's one of the things they say in House Bill 30, they're happy to do. But when you ask, there are occasions where what you get back is --- and I'm sure you all know this --- it took me a moment. I'm like your counsel there. If I knew all of medicine, I would have become a doctor not a lawyer. But they, instead of giving the coroner what they asked for, which is a blue tube of blood, they say, well, we don't have any blue tubes, how about if we send you red tubes. Well, there's a difference. It isn't just somebody just decided, I've got blood from her brain, there's chemicals in those tubes. It makes a difference as to what you can test for. So to suggest that the OPOs can be the same as a --- someone who is forensically qualified to search for evidence, we don't believe that that is an equivalency, and it should not be in House Bill 30.

Let me just, briefly, touch on --- I did want to say one thing and give Dave --- he's got a tough job. He has to prove beyond a reasonable doubt to an entire jury that someone

is guilty. It takes a lot less to convince one person that there's some evidence missing.

The whole point of organ donation has been based upon the dead donor rule. You're supposed to be dead. Now, back in 1968, the Harvard Committee came up with a means and a description of what that death can mean. I mean, we've all thought before that you're kind of stone cold and anybody can tell you, if you're not breathing, you're dead. The Harvard Committee said, well, yeah, that's still one of the potential ways you're dead, the other way is brain death.

The unfortunate thing is there's been about 40 different changes in the four criteria that Harvard laid out. And so you can be declared dead by one hospital or one physician, and if you went to another hospital or another physician, he'd say you're still alive. That becomes the issue, that's why you have some concerns among donors, or at least I would say that I think that is the reason why.

And the other thing is --- that has come up is the DCD death, donation after cardiac death. That's one possibility. And then you also have uncontrolled donation after cardiac death, and that's really where you're out on the street --- you're someplace other than the hospital, and you have a heart attack, the ambulance comes. And in New York City, they're followed by an organ recovery ambulance, so that the minute that the regular ambulance personnel say, we don't

think we can resuscitate you, then the organ recovery ambulance can take over and begin the procedures for organ recovery. Why is that important? Because you say the minute --- in this Bill, I shouldn't point at you, Chairman, and say you said. In the Bill, it says that the minute that anything is done, jurisdiction is lost. The body belongs to the OPO.

Now, another thing comes up, and Dave referred to it, what if --- because we do have great traumatic centers. We've got them in Pittsburgh, we've got them in Dauphin County, we've got them in Philadelphia, we've got them in Lehigh County. We also have --- and I know C.O.R.E., what I've seen --- I have no idea what Gift of Life has spent. C.O.R.E. spent $10 million to build a facility for organ recovery in Pittsburgh.

If you start taking all of these bodies --- and the coroners have been told by C.O.R.E. that they intend to take the body from the hospitals and take it to their facility in Pittsburgh. What happens to the jurisdiction? All of a sudden, is all of the jurisdiction going --- for every criminal investigation going to Allegheny County and Philadelphia County? Do they want that? Let me put the question a different way. Do the other 65 counties want to give up all their jurisdiction? And I leave that for you to decide.

Informed consent, do we really think that when somebody goes to PennDOT, PennDOT says now, you know, when you

check that donor box, you're giving up all your organs, all your tissues. It's being made a gift, which carries with it the ownership to an organ procurement agency. Do you know that some of that may be medical experimentation? Do you really want to give up that all? And some people do and some people don't. As I said, I have a friend whose father wanted to give up his corneas, but nothing else. She would respect that, or should government say, no, you just give up everything?

And the other thing is, and I would echo what Dave has said, I think you need to know, perhaps, a little bit more in terms of what is the issue you're dealing with. C.O.R.E. and Gift of Life have done a tremendous job. They've got national accolades for the number of organs they have procured. But when they talk about whose on the list, who's dying and who's not on the list, why? We ought to know that. And are most of the people on the list for kidneys? We ought to know that. We might want to know with all of the monies that have been sent in to the Governor Casey fund, what's that money being spent for? There are people who have donated and they still owe thousands of dollars in funeral bills.

And maybe we want to know what happens to the organs that are not used? They become medical waste and can be incinerated, they can be thrown into a landfill. Is that what we want? I can tell you that when we have unclaimed bodies, the coroners generally do a service once a year.

So I guess, I would leave you with a fact, which is that please don't ignore the donor. Please don't take away the voice of the donor. And we're all going to be leaving this hearing room in a few minutes. We can forget about the coroners, we can forget about the DAs, we can forget about the victims, but what you can't forget is that you are about to make life and death decisions. And yes, it is a precious gift to give to someone who needs that organ to preserve all life. And frankly, if I was a mother, such as we heard from earlier, and you said to me nothing can be done, I would become your worst nightmare. I can assure you of that. But we've got to have some balance in this Bill. We've got to recognize that the criminal justice system is important to this state as well. Thank you. And I'll try and answer any questions that you may have.

MS. KRAMER: Ready for me? Hello, I'm Ellen Kramer. I'm the local director at the Pennsylvania Coalition Against Domestic Violence, and I, too, want to thank Chairman Cutler, Chairman Caltagirone and the rest of the Committee for inviting me to participate in this proceeding today.

I've had the opportunity to speak with many of you about PCADV donor services, so I won't belabor them other than just to remind you that we support a network of 60-community based domestic violence programs that provide direct services to victims of domestic violence in a wide range of manner.

Shelters, hotline services, legal and medical advocacy and housing, just to name a few. Our medical services help victims rebuild their lives and obtain safety and economic measures, but empower them to leave their abusers and begin their lives anew.

Each year, and I can tell you for the past year we've served over 85,000 people, that includes, men, women and 7,000 children. So our services are very much in demand, and domestic violence is a very real problem in our communities.

It's always a good day when I get to follow Dave Freed in testifying, because I know he can always be counted on to set out a framework and an approach that makes sense, and gives me an opportunity to say, yeah, what he said. So thank you, Dave.

We, too, have worked very closely with the Gift of Life donor people. Jan Weinstock and her colleagues have been collaborative and supportive and empathetic to our concerns. So we at PCADV also believe that we're really close. We clearly support the underlying intent of Gift of Life and this Bill, and we just believe that there are a couple things that still require attention, many of which Mr. Freed already addressed with you today. Personally, as a mother, as an organ donor and even, yes, a grandmother, you know, this testimony today was very compelling. And I would hazard to guess that any of us in the room or heard the testimony and aren't

currently organ donors will be so by the end of business today. So we are very sympathetic to the needs and concerns of people waiting on lists and people who have lost their loved ones and want to make a lasting gift to honor their deceased family members.

Homicide, though, is a very harsh reality of domestic violence. Last year in Pennsylvania there were 158 domestic violence fatalities, 107 of those were victims, and the other 51 included deaths of perpetrators and bystanders. There were men and women, children, people from all economic walks and all sediments of Pennsylvania's communities.

So while we support organ donation and recognize that donors do provide an important second chance for life for many individuals, we can't overlook the likelihood of trauma to surviving children and other family members as a result of the organ procurement process that may fail to prioritize the need of survivors. So we believe that it's essential for surviving loved ones to have the opportunity to pursue justice and overcome the trauma from such a devastating loss. And, therefore, we have four proposals that we think will help strengthen the bill, not big things, and again, we believe not things that should preclude this Bill from eventually becoming law, sooner rather than later.

Our first concern has to do with the authority of an abusive spouse to donate a decedent's organs. So this echos

very closely what Mr. Freed was talking about with Baby Sophia. An abusive partner should not have the final say regarding a victim's anatomical gift, and the Bill needs to be amended to mitigate the opportunity for perpetrator manipulation.

So what we have is spouses, I believe, in the number two position to be able to donate, which in most cases is going to be absolutely appropriate and fine. But in the case where you have an abuser who has actually taken that final horrific step of killing the victim, it is certainly in their best interest to make a quick donation of the body and hope to preclude any further investigation. So we think we need to take a step back and look at how we can strengthen the Bill and not allow abusers to be the person that gives consent where a donor has not already done so.

We're also looking to prioritize investigation of suspicious deaths. And again, echoing what Mr. Freed has always talked about, if there's a reasonable cause to believe that criminal activity is associated with the death, a thorough investigation has to be allowed to take place. We just want to slow down the process and make sure that the burden is shifted to the --- the authority is shifted to the law enforcement to be able to say hold up, we have an investigation that we need to do, and not have to justify that they want to withhold organs. The presumption should be that law enforcement hold onto the body until they're ready to release it.

The prioritization of criminal investigations could be strengthened through a further amendment, authorizing a delay in the notification of an organ procurement organization in cases where the cause of death is ruled suspicious by an investigating body. We also propose an amendment to require the organ procurement representative to make a reasonable inquiry into any civil, criminal or pending investigations where there is an allegation of abuse or other acts of violence. This will just safeguard the opportunity for law enforcement to make their necessary investigation and preserve any evidence that could lead to holding offenders accountable and bringing justice to the surviving members of a decedent's family.

We're also very interested in protecting confidentiality and informed consent. Although coroners, law enforcement officers, attorneys and medical personnel are subject to confidentiality requirements, it's not clear whether an organ procurement representative is also prohibited from disclosing information to the public, including notes and photographs regarding an anatomical gift and the circumstances surrounding a donor's death.

Safety and confidentiality is a cornerstone of victim safety and often also for her or his surviving family members. So while Section 8623 protects the identity of a donor and recipient, the protection doesn't go far enough. We

suggest that organ procurement representatives must be bound by confidentiality regarding the details and information surrounding an anatomical gift and/or any potential donor.

We would go further to request amendments to House Bill 30 and Pennsylvania's Right to Know Law, to protect information contained in a donor registry from public inquiry. We understand that we're looking at either maintaining a registry with the Department of Health, possibly Department of Transportation. Those would otherwise be considered public record subject to Right to Know, and we would encourage the Committee to consider amendment to make sure that those --- that kind of information is protected in a registry maintained by the Commonwealth.

We're also asking that you consider establishing procedures and enact penalties for intrusive protocols. We, too, have heard horrific stories from victim advocacy providers all over the state of organ procurement representatives who may have become a little bit aggressive or intrusive in a family's grieving process. Certainly, this doesn't happen all the time, but it does happen. And while we understand from the Gift of Life professionals that there's lots of training and protocols in place, we would want to make sure that those protocols are codified so that we don't have to leave it to chance whether those protections will be always included in the law.

Mandatory discrete and sensitive protocols have to

be really introduced into the law. We feel very strongly about this. They were removed by amendment in House Bill 30. There has to be significant and meaningful penalties for organ procurement organizations that fail to abide by these standards set forth by the legislature.

So with that, I'm going to thank you very much for your time and attention and your careful consideration not only of our concerns, but of our panelists, and certainly the people who have testified before us today.

CHAIRMAN CUTLER: Thank you all for testifying. Chairman Caltagirone?

CHAIRMAN CALTAGIRONE: Yeah. I just want to share with members and the audience here today, that I had the privilege to have dinner with Dr. Fung, who had done the double transplant on Former Governor Casey, now deceased, out in Pittsburgh after that had taken place. And one of the things that I might want to share with you is that I was totally impressed the next day when he took me on tour of the research facilities at the Pittsburgh Hospital where they were doing the research, and it was amazing that time what they were replicating with different animals about us and our genetic experience with different animals for heart valves, ears and other things.

So I've witnessed firsthand, you know, how that money was being spent in the research department on what they

were replicating to extend our lives. But it, you know, was an interesting experience also that there was a double transplant with our former governor.

I just wanted to mention that to the members, that this has been going on for some time. And I share with you the concerns that you raised, and I know that Representative Petrarca, whose profession is an attorney, he, I think, is going to take to heart the suggestions that you've made, and we have a number of attorneys on the Committee as well as staff attorneys that I think really want to address those issues and move the Bill forward with those concerns. Thank you, Mr. Chairman. Thank you, testifiers.

CHAIRMAN CUTLER: Thank you, Chairman Caltagirone. I just want to go to the Chairman's comments. It seems to me, I certainly don't want to put words in your mouths, but I kind of generalized the issues that you raised into three categories. The first one being the idea of truly informed consent and revocation of that consent, the second being jurisdictional questions upon transport of the patient, and third being the ongoing criminal investigations or potential for individuals who are under investigation, being those who can provide the consent in item number one.

I certainly, like Dave Freed said, I think that they're not insurmountable, I think that all of those can be appropriately worked out. And I guess --- I don't need an

answer now, but I was looking --- kind of flipping through the Bill as you all were testifying, and I know that on pages 9, specifically lines 10 and 11, and carried on to page 10, 1 through 7, it talks about the idea of an anatomical gift absent any kind of known objection. Because I believe, Susan, you raised the point --- and I had a friend who did this. She wanted to donate everything but her eyes. She was kind of the opposite of your friend, for whatever reason, but that was her request. She lives in Maryland. And unfortunately, she was found to be not a suitable donor, because of her other medical complications.

But it was something that I completely understand. I mean, myself, I've been a donor since my early 20s because of my own family history. And my wife, I had pretty much given her carte blanche through my living will that says, you know, feel free to donate and use as whatever seems appropriate at the time. But I also think that it highlights the need, specifically, after --- should there be any changes that I think we all as organ donors are going to have re-visit what we specifically said before, because this law obviously will impact it as well.

With that, I know that there's some more questions. I look forward to working with each of you as individuals in your groups, because like you, Mr. Freed, I think it's absolutely correctable and certainly look forward to working

with that. Representative Petrarca?

REPRESENTATIVE PETRARCA: Thank you, Chairman. I just have a few comments. I guess, Mr. Freed and Ms. Kramer, I thank you both for being here, certainly, and more so meeting with the organ procurement organizations and everyone interested in doing what we can to pass this legislation to make more organs available again for those in need as I said earlier. And I think we can --- as Chairman Cutler said, I think we can work through some of these things. Some of them I may see a little differently in terms of, you know, are they essentially happening, and does the Bill deal with that, what have you. But again, I think we can work through these things.

With relation to the coroners, though, I just want to say to the panel that Ms. Shanaman did not say that this Bill diverts jurisdiction from them, and that's because there's nothing in this legislation that takes away jurisdiction or final say from coroners in Pennsylvania. There just is not --- I mean, we've heard some stories about Texas or Michigan or New York, but there is nothing in this legislation that does not give them the ability to deny a transplant or takes away their jurisdiction. It's just not in this piece of legislation.

And with regard to the coroners again, I've been trying to meet with you folks for two, three years and the coroners, you know, unlike these other two groups, refuse to meet with us or to discuss anything regarding this legislation.

I'm certainly glad you're here today to hear what you have to say, but hopefully we can move forward and work through all these concerns to get a piece of legislation that we can pass through this general assembly.

REPRESENTATIVE CUTLER: Thank you. Representative Hackett?

REPRESENTATIVE HACKETT: Thank you, Chairman Cutler. And Joe, thank you for bringing this Bill forward. I appreciate all the hard work that you put into this. I guess first for Counsel, does the National Association of Medical Examiners report this? Does anyone know that yet? If not, we can get to that later. We can talk to them maybe?

ATTORNEY DYMEK: Yeah. We're still on the fact gathering stage with this as councilman on the staff, so I don't have positions from groups aside from those who have appeared today?

REPRESENTATIVE HACKETT: Thank you, Tom. I think that a lot of my questions were answered already by District Attorney Freed. Thank you for your questions today. I did see some communications and some concerns from the coroners and medical examiners, and they seem to be pretty adamant saying that a lot of the OPOs were very aggressive towards the coroners and the medical examiners, sometimes to the point of interfering with investigations. So that, you know, made the hair stand up a little bit on my neck. And some to the point

of even harassment.

And Joe, I would like to offer Dr. Hellman down in Delaware County, the medical examiner --- I'd like to facilitate a meeting. I'm sure he would sit down with you and help you work through some of these struggles that we're bumping into here with the Bill. He did give me the okay to put that out there today.

I have another question, I guess, as it would pertain to cost, and I think Section 8627(c) talks about providing reimbursement, you know, for attending the autopsy. I just was concerned if that will include the coroners --- you know, the consulting physician, if it would cover that, and again, we can answer that at a later time, too, when we start working on it and digging in a little bit.

So if somebody can answer me this, so as an organ donor, if you choose to be an organ donor, presently it is all or nothing, is that the way it is, or no, can you pick which organs you're willing to donate? Because I think we'll have a spike in increased donations if you could pick, but if that's the way it is, and forgive me I'm not in the weeds?

CHAIRMAN CUTLER: I can give you how my advanced directive is set up. I'm donating everything, but we as individuals can prohibit or not prohibit as we see fit under current law.

ATTORNEY FREED: Representative, some of the

discussions that we've had, and I appreciate your input, because I'll tell you a little anecdote from when we had our meeting in Pittsburgh and we had some of our friends from the Allegheny County DA's office and Dr. Williams, who I have a tremendous relationship. We have our friends from the Philadelphia District Attorney's office who have a wonderful relationship with their medical examiner. And you have myself and District Attorney Eddie Marsico, who have really good relationships with our coroners and we've been able to get things worked out.

So in a lot of places this process works, and a lot of places there are issues. And you know, we've heard many stories, and these are things that we need to be cognizant of. In terms of the cases that I've been able to work out, what we've been able to work out is preservation of certain organs and donation of others. For example, the one that I had back on Labor Day is a tragic case of an eight-year-old being shot in the head by his six-year-old brother. And we've charged the mother in that incident with endangering their welfare, and frankly, actually involuntary manslaughter.

But what was presented to us was, you know, this boy is brain dead, but his organs are in great shape, and we were able to work out something. Because it wasn't a case where there's a question about what had killed him, there wasn't a question about degree of homicide, you know, the things that

often become an issue that would necessitate a full scale autopsy were not in play there. So we preserved the brain and the head area and were able to make donation for the rest.

So certainly that's an advisable thing for two reasons. One, investigative purposes, if we can work out an accommodation where we can preserve some and donate others. And secondly, you know, for all us and our free will and individual choice, certainly will be able to donate what we want to and not donate what we don't want to.

CHAIRMAN CUTLER: Thank you. Representative Saccone?

REPRESENTATIVE SACCONE: Yes. Thank you for your testimony. Just a quick question. How do you balance the presumption of innocence when you say an accused --- an accused spouse could lose his consent for donation? Do you have a suggestion on some balance going forward?

MS. KRAMER: Well, I would suggest when there is a record or evidence of domestic violence that the presumption would be that there would be no donation pending further investigation of the particular homicide.

REPRESENTATIVE SACCONE: Mr. Freed, do you agree with that?

ATTORNEY FREED: Well, yeah, as a practicing attorney, and I'm proud to say that I was actually in court this morning doing bail reduction. And as District Attorney,

you don't get to go to court very often.

Certainly, if there's an investigation going on or an investigation pending, those are the situations where we would have grave concern. What the process is about how we make that determination, I think is something that's open for debate and something we have to have a discussion on, whether there's a process laid out, whether that involves some sort of court proceeding showing, you know, those are some possibilities.

REPRESENTATIVE SACCONE: Thank you.

CHAIRMAN CUTLER: Thank you. Representative Delozier?

REPRESENTATIVE DELOZIER: Thank you very much. My question, actually, did hit on a little bit on my first question, which is the preservation of some in the sense of the types of organs, obviously, if there's an injury to the head, the rest of the body is not part of the criminal case, which kind of leads into --- and I need to get a medical update on exactly how the coroner acts, and why the harvesting and the coroner cannot, you know, work together on it. So that's something I need to learn, as to the medical and where the preservation is and the criminal side of things. That's not something I'm aware of.

But that kind of leads into the second part of my question, which is really a matter of it was stated earlier

that over one percent of those that passed are possibilities because of the brain dead to be an organ donor. How many of that one percent, one to two percent that was given earlier, how many of that one to two percent are actually criminal cases that you would be concerned law enforcement needs to be involved?

ATTORNEY FREED: It's a smaller number than that. I can give you a little bit of a perspective. And this is really where the rubber hits the road as it relates to coroners, medical examiners and prosecutors.

Dr. Williams in the Baby Sophia case, he had an opinion about what was necessary to prosecute the case. The District Attorney, his responsibility is to prosecute the case, had a different opinion.

And what we get involved in --- obviously an autopsy is done to show cause and manner of death. It also excludes everything else. So depending on the case, if you have someone with six bullet holes in their head, a pretty good idea that you don't need to worry about the shape of the other organs. Contrast that with a couple of cases that I've done, particularly murders of children where there was a question about --- and a battle in court about what actually caused that death.

I've tried a starvation case and there were all sorts of competing theories. There was a huge battle of

experts. That's a case where I needed to know what exactly caused it and what didn't. So that's where the conflict --- that's the point where the conflict is going to take place. And I think it is a very small number of cases, but they are the important cases, because they're cases where we probably have someone who has died as a result of criminal activity, and that's why there is so much interest from us, from the coroners on these issues.

REPRESENTATIVE DELOZIER: And I want to err on the side of law enforcement, certainly when there is a victim, because justice is deserved. I also think that we can --- and I think it has been stated that there can be a balance, because there's two victims. There's the victim of the criminal side of things, which you have every right to be able to prosecute, and I would wholeheartedly support, then on the other side is the victims of the families that have very ill individuals.

So neither of them asked for it, to be a part of the system, whether needing that donation or needing justice. And I think they both, unfortunately, are warring with each other in this particular case and are both very valid. So I think, you know, if we can move --- you know, with it being such a small number of cases, and some of the issues that have been raised, I certainly hope that we can continue the conversation and come to some fruitful end, because any time that we can save a life with a donation, I think we should be working

towards that with the idea of obviously getting that justice for that victim, because there's no better result for a victim or a family's victim.

ATTORNEY FREED: Absolutely. And I think we share your goal and we're sensitive to that issue.

CHAIRMAN CUTLER: Thank you, Representative Delozier. Actually, as a follow-up to you, Mr. Freed, I'd have this question. And it starts with the caveat I never practice criminal law, but it's my understanding, and please correct me if I'm wrong, wouldn't the individual be tried in Clearfield County in that particular case, okay, because it seems to me and maybe this is an oversimplification, it should simply link the jurisdictional --- you know, the final approval with wherever the criminal case would proceed. Because that's already an established body of case law.

ATTORNEY FREED: Right. That's certainly a possibility. And that's one manner in which this can be addressed. You know, the concern --- you know, the reality, frankly, is that so a case that's a head injury, that's a potential shaken or shaken impact case, there will be a battle there over that.

And then with respect to my colleagues who primarily practice criminal defense, they're going to do the best they can to zealously represent their client, and there are going to be lots of questions about the other potential medical

conditions of that child. So that's really the point of the issue, but that is one way --- I think, a relatively simple way to attack that issue.

CHAIRMAN CUTLER: All right. Thank you. Thank you all for sharing. I look forward to working with you as we move forward.

ATTORNEY FREED: Thank you very much.

CHAIRMAN CUTLER: With that, we'll call up our final panel, Cheri Rinehart and Dr. Sam Gulino.

MS. RINEHART: Saying good morning or good afternoon.

CHAIRMAN CUTLER: We did cross the afternoon threshold, so I need to change. My apologies. Thank you both for joining us. You may proceed.

MS. RINEHART: Thank you for the opportunity. I'm Cheri Rinehart. I'm President and CEO of the Pennsylvania Association of Community Health Centers, and I also serve as Chair of the Commonwealth's Organ Donation Advisory Committee that was established by the Act 102 of 1994, our last update to Uniform of Anatomical Gift Act.

I also bring the experience that I have as a registered nurse, and from serving 17 years as Vice-President of the Hospital and Health System Association of Pennsylvania, HAP, where one of my areas of responsibility was organ and tissue donation.

For those of us who were around back in 1994, some of this feels like, in the words of Yogi Bear, déjà vu all over again with the resistance. Although the resistance at that time, frankly, was in large part from the hospitals. And when we looked at the reasons that we were not getting people to give the permission for donation at that time, or that they weren't being given the opportunity for donation at that time, there were a number of things.

It was rushed hospital staff who were busy dealing with patients, and then were being asked to offer the opportunity for donation to families of the deceased. It was varying degrees of experience, expertise, comfort with our family donation option, and frankly, a lack of expertise in many cases on understanding donation and an inability to answer the questions that were asked by families.

And we also found that having the people who were caring for the patient when they became --- asking a donation decision when they became the deceased was a difficult thing for the staff as well as difficult for the families. And that has been --- that was validated scientifically where it showed that decoupling that declaration of death and sharing with the family that your loved one has died, with the opportunity to donate increases the donation --- the rate of donation.

So Act 102 aimed to address all of those things. You would think that hospitals would have embraced that

wholeheartedly, but it was change, and there was some resistance that we were taking away from their jurisdiction and authority. Does that sound familiar today? But I will tell you, after it was implemented, you would be hard pressed to find hospital personnel who don't believe the system that we have in place now was better than what we had in place when Act 102 was passed.

And I think we'll find the same thing with this Bill. I think a lot of the resistance is due to fear of change and the resistance to change. We're not trying to usurp authority through it. We're trying to support increased collaboration. It worked on the hospital side. I think it will work with the increased collaboration that this supports.

Based on that prior experience and now the fact that in my testimony it says 43 states, but I'm being told it's now up to 46 other states have implemented similar provisions and have had very positive outcomes, I think we will see the same thing here. And when I say positive outcomes, I truly mean for all stakeholders, whether it's deceased, their loved ones, the hospital personnel, the coroners, those that have tragically lost someone, everyone. If we work together collaboratively on this legislation and on implementation of it, I think that we can get there.

I have had the honor over the course of the last, several decades of working with organ and tissue donation, of

speaking with a lot of families who had to make that decision, and recipients, and it is an honor. And I will tell you, to a person, I've never spoken to someone who has made the donation decision or someone who supported the donation decision that was already made by their loved one, and that is the idea. We want people to be able to make an informed decision before they die so that it makes it a lot easier for all of us, whether it's the hospital, the organ procurement organization, the family. That's why the education pieces are in this legislation, so that people can make informed decisions.

I will tell you in my current role, my health centers serve over 700,000 individuals, and they tend, in large part, to be disproportion in minorities, underserved. And there have been a lot of miss and misinformation that have been passed down for generations. And this Bill gives an opportunity for young people to get education to make an informed decision, whether that decision is to donate or not to donate, that the decision is being based on fact, not fiction. And I think that's important as well.

I will tell you I have had also a lot of opportunities to have responses from people who were astonished to know that if they had made a donation decision, that it could be overridden by the family or someone else. To me, that is part of my estate when I die. I have determined what I want to happen with my body, and I will haunt my family if they

would override that decision. And I think this Bill solidifies that we would respect first-person authorization and honor it whenever possible. And I think that's critically important.

I think, too, with the education pieces we've seen what it's done in other states, how it's raised donation rates, because people are making educated decisions. And the education for health professionals is also critically important. My husband will tell you, even though I have R.N. after my name, I'm not the person he would go to if he was hurt anymore. It's been a long time since I served as a real nurse. But because I have R.N. after my name, a lot of people come to me and ask my opinion. And health professionals don't have organ and tissue donation in many of their professional curriculums as part of that curriculum. And I think it's important whether they're being coined as the trusted neighbor or officially as the trusted health professionals, that they have enough education that they can give clear guidance.

I do believe that the Bill will streamline the process. I believe that it supports collaboration, that it does not usurp authority or jurisdiction. I agree we should have a list of who is unable to donate, who wanted to, and I think through the collaborative approach we will find that. I think we owe it to the public to support them in making an informed decision. Again, whether that decision is to donate or not to donate, I think we owe it to the health professionals

to make sure they have the education to give informed information.

I think we owe it to those waiting, like Tony. I think we owe it to the families who have experienced a very tragic loss. And we don't want them to have to experience, as Amanda's mom talked about earlier, what feels like a second death when they're not able to donate. I think we owe it to the coroners who have a very tough job and deserve to see something good come out of tragic losses. And I think overall we owe it to the Commonwealth to reassert ourselves as a leader in organ and tissue donation. And I think this Bill gets us there, and that we're getting closer with the amendments that have made through the Senate version.

DR. GULINO: Good afternoon, Mr. Chairman and members of the panel. Thank you for inviting me to provide testimony in favor of House Bill 30, the Donate Life PA Act. My name is Dr. Sam Gulino, and I'm the chief medical examiner in Philadelphia where I've been for the past six years.

To give you a brief summary of my background, I'm a forensic pathologist, and I've been working full time in the field of medical legal death investigation for nearly 20 years. I've worked in and with jurisdictions ranging from larger centers like Philadelphia to small sparsely populated rural counties in Missouri and Florida, and nearly every size jurisdiction in between. I personally conducted more than

5,000 autopsies, including hundreds of homicide cases. And in my roles as Chief Medical Examiner in Philadelphia and as the Deputy Chief Medical Examiner in Tampa, Florida, I've been responsible for overseeing death investigation systems that evaluate tens of thousands of cases in total.

As you've heard today, medical examiners and coroners do have an obligation to investigate each death that falls in their jurisdiction, and to provide information to law enforcement. And my simple message today is that there is nothing in House Bill 30 that contradicts or conflicts with that obligation.

There are two portions of the Bill that specifically speak to the role of the coroner and the medical examiner. The first is on page 18 where Section 8617 is amended to require a medical examiner or coroner to report deaths occurring outside the hospital to the organ procurement organization through a mutually agreed upon protocol. Since these are individuals pronounced dead outside of the hospital, these cases are suitable only for a tissue donation, not for organ donation.

Tissue donation is not dependent on maintaining a beating heart donor in an intensive care unit. And so the medical legal death investigation is able to proceed while the donor potential is being assessed and next of kin authorization is sought. In many cases, tissue donation can occur even after the autopsy is completed.

In January of 2013, the Philadelphia Medical Examiner's Office entered into such a protocol with the Gift of Life donor program. Twice a day a number of my staff faxes a list of newly reported cases to Gift of Life and then a coordinator from Gift of Life follows up by contacting our office for information in those cases that meet initial screening criteria.

This collaboratively developed process takes only a few minutes out of our day, but has had significant results. Since the beginning of 2013, a total of 23 additional donors have resulted from this direct referral process in Philadelphia alone. That's 23 families who are given the opportunity to choose tissue donation and who previously would not have been able to make that choice. The tissues from these 23 donors have the potential to benefit literally dozens of living patients.

The second portion of the Bill that directly affects coroners and medical examiners is on page 39, adding Section 8627. This section addresses situations in which a medical examiner or coroner is considering denying removal of organs for transplantation. It's important to note that this section deals only with organ donation and not tissue donation. Most tissue donation involves tissues that are banked for later use in surgical procedures. Organ donation, on the other hand, as you've heard today, results in immediate lifesaving transplants

for patients with life-threatening illnesses. It is, therefore, sensible to require collaboration and careful deliberation before denying organ transplantation.

House Bill 30 does not restrain coroners or medical examiners from denying organ donation. It merely requires them to consider that decision very carefully. If a medical examiner or coroner wants to deny transplantation of an organ, the Bill would require that they did not --- that they or the designee be present in the operating room to see the organ firsthand, and if necessary, request that a biopsy be taken of the organ. If the coroner or medical examiner still wants to deny transplantation, they must give their reasons in writing.

If a patient with a life-threatening illness gets denied an organ transplant and if a family who has authorized a life-saving organ donation is to be told that it cannot proceed, it is very reasonable to ask that the decision be fully informed and the specific reasons for denial be documented and stated.

When a collaboration occurs between death investigation officials and organ procurement organizations, compelling reasons to restrict lifesaving organ donation are unlikely to be found. In my experience, organ procurement organizations are willing to go to significant lengths to assure that the concerns of the coroner and medical examiner are addressed so a donation can proceed.

In my own practice, depending upon the nature of case, this is included allowing me or my staff into the intensive care unit to take photographs of organs for donation, getting additional x-rays or other tests to document the condition of a particular organ, taking digital photographs of the organs as they are being removed from the donor, or allowing me or my staff to be present in the operating room to view the organs firsthand.

In each case, this collaboration permitted donation to proceed. In all of the cases I've personally examined, in all the cases that have been handled by the pathologists I have supervised, I am unaware of any case in which permitting organ donation has hampered the preservation of evidence, has hampered the determination of cause and manner of death or has hampered successful prosecution, nor has any case been shared with me by any colleague in my field.

You heard in previous testimony about a paper that was published in the Harris County Medical Examiner in Houston, Texas. I'm very familiar with this paper. It describes five cases in which a cause and manner of death after organ donation was undetermined. They describe each case in detail, and in none of those cases do they describe any effort that was made between the Harris County Medical Examiner and the organ procurement organization to collaborate to gather data on organ function before the transplant took place. Furthermore at the

end of that paper, they admit, and this is a direct quote, in some or all of these cases, if the autopsy had been complete, the cause of death may very well still have been undetermined.

House Bill 30 has the potential to greatly enhance organ and tissue donation, benefiting both the transplant recipients and the families of donors without impairing medical examiners or coroners from satisfying their statutory obligations. Thank you very much for allowing me to address you today. I'd be happy to answer any questions that you have.

CHAIRMAN CUTLER: Thank you both for testifying. We'll start, Counsel Dalton has a question.

ATTORNEY DALTON: Thank you both for coming here. I have a question for you, Doctor. And I have to admit that, again, I don't know anything about medicine, other than what I learned from going to my own physician if I have something that's wrong with me. So from what I understand, there's a distinction about death, that under current law, it has to do with brain death, and under the Uniform Act, as it's proposed, it would be cardiac death. And my lawyer's brain tells me that's a distinction with a difference, but I can't figure out what that is. Can you speak to that, please? Why that's important?

DR. GULINO: I'm not entirely sure of the question, but I will do my best to try and answer it. So medical examiners are not involved in the determination of death prior

to organ donation. That determination is made by hospital personnel. And uniformly when you're talking about organ donation, historically, you've been talking about brain death, where the person's heart is still beating.

There has been, in the last several years, the addition of cases, where they can donate certain organs after cardiac death, but it has to be done very rapidly. Are those the situations that you're speaking about?

ATTORNEY DALTON: Again, I've got to be honest to say I don't know, I just know it's important, and I'm trying to figure out what that is.

Can you just also answer this question, please, again, because I'm a neophyte. Tissue --- I imagine organs being a heart or a lung, but can you please tell us what a tissue would be?

DR. GULINO: Sure. So potential tissues that can be donated are things like skin, which can be used in skin grafts and burn patients, bones for people who have orthopedics procedures, heart valves which can be implanted in the patients requiring open heart surgery. Corneas from the eyes in people who have vision problems. Whereas, organs refer to full organs such as an entire heart, a liver, and now they can actually take a liver and split it into one or more parts and potentially go to two potential donors.

But it refers to using an entire organ as opposed to

tissue. The primary difference between the two is that tissue donation is not immediately lifesaving. It certain is life enhancing, but these tissues are not used the same day or the next day or even the next week. These tissues go into storage while additional testing is done. They're processed into particular forms that are useable by surgeons. So they may remove an entire bone from the leg, but that may be used to create small discs of bone that a surgeon might use or pieces of bone, or even bone dust that they use in surgery, whereas organ donation, literally they're taking an organ out of one person, transporting it to a new hospital and transplanting it into a person that same day.

ATTORNEY DALTON: Thank you.

CHAIRMAN CUTLER: Representative Costa?

REPRESENTATIVE COSTA: Thank you, Mr. Chairman. Thank you, panel, for being here. Dr. Gulino, good seeing you again, sir. I, too, agree with you and my good colleague, Representative Petrarca, that there's nothing in this Bill that there's nothing in this Bill that prevents a coroner or a medical examiner from doing their job, okay, or does it give anybody right over their decisions.

Being a 27-year police officer, I initially was against the of the idea of Bill because I thought, too, but more reading and talking with medical examiners like Dr. Williams and stuff, I see that it doesn't. And it disturbs me

that the coroners are coming out against this. And what I say is misrepresenting what it can be. You know as well as I do that we can exhume a body years later and find a cause of death. And you don't get all the bodies in perfect condition, but the question I have for you is, if there's trauma to the upper torso, the kidneys and stuff, would they be affected? Would there be any reason for a coroner or medical examiner to deny those organs?

DR. GULINO: My personal or professional experience is that there's never been a reason to deny an organ donation. And that is because, rather than simply relying on the autopsy examination after the person has died, we basically split the autopsy in two parts. We have the autopsy that's done that looks at whatever is given to us, and then we have all the information that we can gather while the person is still maintained in the hospital prior to donation.

And so Gift of Life will ask us for our permission to proceed, and the doctor then has the chance at that point to collaborate with them and say, I need to understand if the liver was injured, and they will do an ultrasound of a liver or x-rays that we asked for to look for fractures or whatever tests. I've never had a situation with any organ procurement organization that I've worked with, and I've worked on a number of jurisdictions, where those requests have been denied. And what those tests do is they allow us to document either a

normal organ functioning or a normal organ anatomy so that we can feel comfortable saying it's okay to proceed with the donation of that organ, and that's basically saying that once I'm sure that organ was normally functioning by virtue of what other test is done, and the fact that it is now functioning in a living person, and keeping that person alive, that is plenty to satisfy me being able to say that organ was normal and gets past the obligation that I have to rule out other potential causes of death.

REPRESENTATIVE COSTA: Common sense on forming, I guess; right?

DR. GULINO: I hate using common sense, but absolutely.

REPRESENTATIVE COSTA: Okay, Doctor. Thank you, Mr. Chairman.

CHAIRMAN CUTLER: Representative Saccone?

REPRESENTATIVE SACCONE: Yes. Thank you for your testimony. Ms. Rinehart, I'd like to ask you, I'm not clear --- I see the definition of an organ procurement organization in the Bill, but are they typically non-profit organizations that are strictly out of the welfare of patients, or do they derive money from harvesting organs?

MS. RINEHART: They are non-profit organizations. And they are, as Mr. Nathan outlined earlier, very heavily regulated. Actually, his side was pretty simple compared to

the complexity of all the regulatory organizations overlooking them.

REPRESENTATIVE SACCONE: Thank you for clearing that.

CHAIRMAN CUTLER: Thank you both for testifying. That concludes the formal testimony that we had scheduled this afternoon. I want to thank everyone for their patience and their attention, as well as all the information that they provided. I'd like to note for the Committee members who are present, we've also received submitted written testimony from several individuals here at the bottom of the agenda.

Additionally I'd also like to make note that we will leave the record open to receive additional written testimony should any other individuals who are unable to attend or had further comments, they'd be able to do so.

I would simply say as a co-sponsor of the Bill, Representative Petrarca, I just want to thank him for his work on this Bill. It's been a pleasure to work with him thus far. I think that one of the main goals of this hearing was to get all of the stakeholders in the room to air some of the concerns, and I think in that regard this has been a success. I want to thank everyone for participating.

It's my intention to follow up with each of the individuals and the prime sponsor of the Bill and hopefully work towards some resolution of the areas that we identified

earlier today. In addition, I intend to work with the Committee as well as the staff, who have been diligently working on this topic thus far. And we'll make some formal follow-up with them at a later time.

I really think, as was pointed out earlier by one of our colleagues I think the individual cases that we're seeking to target, whether they be specific criminal investigations or questions of consent, in the overall scheme of things, are few in number. I do not, in any way, intend to denounce their importance, because I think that they're vitally important to each of these individuals, whether it be a criminal prosecution or a real question of informed consent. I think those are all valid concerns, but concerns that I think are completely workable from a legislative standpoint. I look forward to working with each of you as we go forward.

I want to thank everyone again for their time, and the members who attended, thank you very much for your attention. And I appreciate everyone coming out today. Thank you.

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