

COMMONWEALTH OF PENNSYLVANIA
HOUSE OF REPRESENTATIVES

HEALTH COMMITTEE
PUBLIC HEARING

STATE CAPITOL
HARRISBURG, PA

IRVIS OFFICE BUILDING
ROOM G-50

THURSDAY, APRIL 22, 2021
9:03 A.M.

PRESENTATION ON
PRO-LIFE/ABORTION, PART III
DOWN SYNDROME

MEMBERS PRESENT:

HONORABLE KATHY L. RAPP, MAJORITY CHAIRWOMAN
HONORABLE STEPHANIE BOROWICZ
HONORABLE JOHNATHAN D. HERSHEY
HONORABLE KATE A. KLUNK
HONORABLE ANDREW LEWIS
HONORABLE BRAD ROAE
HONORABLE PAUL SCHEMEL
HONORABLE TIM TWARDZIK
HONORABLE DAN FRANKEL, DEMOCRATIC CHAIRMAN
HONORABLE JESSICA BENHAM

MEMBERS PRESENT VIRTUALLY:

HONORABLE TIMOTHY BONNER
HONORABLE JIM COX
HONORABLE VALERIE S. GAYDOS
HONORABLE DAWN W. KEEFER
HONORABLE CLINT OWLETT
HONORABLE DAVID H. ZIMMERMAN
HONORABLE MORGAN CEPHAS
HONORABLE ELIZABETH FIEDLER
HONORABLE STEPHEN KINSEY
HONORABLE BRIDGET M. KOSIEROWSKI
HONORABLE RICK KRAJEWSKI
HONORABLE BENJAMIN V. SANCHEZ

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*Pennsylvania House of Representatives
Commonwealth of Pennsylvania*

COMMITTEE STAFF PRESENT:

WHITNEY METZLER

MAJORITY EXECUTIVE DIRECTOR

MAUREEN BEREZNAK

MAJORITY RESEARCH ANALYST

LORI CLARK

MAJORITY LEGISLATIVE ADMINISTRATIVE ASSISTANT II

ERIKA FRICKE

DEMOCRATIC EXECUTIVE DIRECTOR

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SUBMITTED WRITTEN TESTIMONY

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(See submitted written testimony and handouts online.)

1 P R O C E E D I N G S

2 * * *

3 MAJORITY CHAIRWOMAN RAPP: Good morning, Members,
4 and good morning, members of the public. Thank you for
5 joining us today. And this is the third, I believe,
6 hearing on pro-life/abortion issues, and today, we will be
7 more specifically talking about Down syndrome.

8 We do have several testifiers. And, Members, for
9 your information, we will have Ms. Sheaffer testify, and we
10 will have questions, and then the three parents we will
11 have as a panel and then questions, and then Karen Gaffney
12 and then questions, and then Michele Clemens, and
13 questions.

14 So at this point in time I would ask the Members
15 and the audience here to please silence your cell phones.
16 The meeting is being recorded.

17 And I am the Majority Chair of the House Health
18 Committee, State Representative Kathy Rapp. I represent
19 Warren, Forrest, and Crawford. And we'll go around the
20 room with the Members who are present, and please introduce
21 yourself, Members, starting with Representative Frankel.

22 DEMOCRATIC CHAIRMAN FRANKEL: Representative Dan
23 Frankel, Minority Chair of the Health Committee, and the
24 23rd Legislative District in Allegheny County, city of
25 Pittsburgh. Thank you.

1 REPRESENTATIVE SCHEMEL: Good morning. I'm Paul
2 Schemel. I represent portions of Franklin County.

3 REPRESENTATIVE LEWIS: Andrew Lewis, I represent
4 the 105th District in beautiful Dauphin County.

5 REPRESENTATIVE ROAE: Brad Roae, District #6,
6 portions of Crawford County and portions of Erie County.

7 REPRESENTATIVE TWARDZIK: Tim Twardzik, the
8 123rd, Schuylkill County, where we enjoyed snow yesterday.

9 REPRESENTATIVE BENHAM: Jessica Benham, 36th
10 District, Allegheny County.

11 REPRESENTATIVE BOROWICZ: Stephanie Borowicz,
12 76th District, Clinton and parts of Centre County.

13 MAJORITY CHAIRWOMAN RAPP: And Members who are
14 joining us virtually, if you would like to introduce
15 yourselves quickly. Anyone?

16 REPRESENTATIVE BONNER: Tim Bonner, parts of
17 Mercer and Butler Counties.

18 REPRESENTATIVE KOSIEROWSKI: Representative
19 Bridget Kosierowski, Lackawanna County.

20 REPRESENTATIVE OWLETT: Representative Clint
21 Owlett, 68th District, all of Tioga, parts of Bradford,
22 parts of Potter Counties.

23 REPRESENTATIVE KEEFER: Representative Keefer,
24 York County.

25 REPRESENTATIVE KRAJEWSKI: Representative Rick

1 Krajewski, Philadelphia County.

2 REPRESENTATIVE FIEDLER: Representative Elizabeth
3 Fiedler, south Philadelphia.

4 REPRESENTATIVE SANCHEZ: Good morning, everybody.
5 Ben Sanchez from Montgomery County.

6 MAJORITY CHAIRWOMAN RAPP: Thank you, Members.
7 And at this point I believe Ms. Sheaffer is with us
8 virtually. Do we have any of our other testifiers with us
9 virtually at this point in time? Oh, and Donna Greco.

10 MS. GRECO: Yes, good morning. This is Donna
11 Greco, and I'm joined by Barbara Sheaffer. Thank you.

12 MAJORITY CHAIRWOMAN RAPP: Okay. Thank you for
13 joining us today. And at this point in time I will ask
14 that you would please raise your right hand.

15

16 (Witnesses sworn.)

17

18 MAJORITY CHAIRWOMAN RAPP: Okay. Thank you so
19 very much, and you may begin.

20 MS. GRECO: Thank you so much. Good morning,
21 Chairwoman Rapp, Chairman Frankel, and Members of the House
22 Health Committee, and thank you for inviting the
23 Pennsylvania Coalition against Rape to join you at today's
24 hearing. My name is Donna Greco, and I'm joined by Barbara
25 Sheaffer. I'm the Policy Director at PCAR, and Barbara is

1 the Medical Advocacy Coordinator at PCAR. And together, we
2 have worked to support survivors of sexual violence for
3 over 25 years.

4 It's been a privilege to work with Barbara and
5 with Members of the House and Senate over the years to
6 advance legislation, to better serve victims of sexual
7 violence throughout the Commonwealth, and we really thank
8 you all in this Committee for working with us on that. We
9 are grateful to be here today.

10 As you may know, PCAR was established in 1975,
11 and our mission is to eliminate all forms of sexual
12 violence and to advocate for the rights and needs of
13 survivors. This mission is mobilized in partnership with
14 the network of rape crisis centers that serve all 67
15 counties throughout Pennsylvania, and these centers provide
16 crisis response and longer-term support and therapy to
17 approximately 33,000 victims per year, and this includes
18 about 3,500 children and their families.

19 Rape crisis centers also worked to engage
20 community members in efforts to stop sexual violence from
21 occurring in the first place using public health practices
22 to uproot risk factors that contribute to this public
23 health problem.

24 We are grateful we were invited to talk with you
25 today because we do feel that conversations about

1 reproductive healthcare are stronger when they're also
2 informed about the perspectives of rape crisis centers and
3 the survivors that they serve. So our testimony today will
4 focus on these intersections between sexual violence,
5 reproductive coercion, and pregnancy, as well as abortion-
6 seeking behaviors among survivors of sexual violence. We
7 will share some data from the research as much as possible
8 with the caveat that this is a very understudied area of
9 sexual violence for many reasons that we'll discuss, and we
10 also do recognize and respect that this hearing is much
11 broader, but given PCAR's scope and mission, we do hope the
12 information we share with you today will be useful and
13 beneficial as you continue to look at policies and
14 practices related to reproductive healthcare.

15 We want to start by saying that PCAR strongly
16 supports a full range of reproductive healthcare options
17 for victims of rape and incest, and this includes abortion
18 services. This policy position guides our legislative
19 stances, as well as our programmatic standards locally with
20 rape crisis centers, and we believe firmly that victims
21 should be afforded unbiased information about their rights
22 and the available services when they are faced with a rape-
23 related pregnancy.

24 So, as you may know, sexual violence remains a
25 pervasive and traumatic public health problem affecting

1 Pennsylvanians, the Nation, and the world. According to
2 the National Intimate Partner and Sexual Violence Study,
3 nearly one in five women and one in 38 men have experienced
4 rape or attempted rape during their lifetimes. NISVS also
5 tells us what we've known for many years, that sexual
6 violence starts early, sadly and tragically in childhood,
7 with one in three female victims experiencing rape between
8 the ages of 11 and 17, and one in four male victims
9 experiencing rape before the age of 10. And we know that
10 the overwhelming majority of perpetrators of sexual
11 violence are known and trusted by victims.

12 We wanted to spend some time talking about what
13 is known related to rape-related pregnancy and reproductive
14 coercion. As staggering as the statistics are about the
15 prevalence of sexual violence, we know that is only the tip
16 of the iceberg given that sexual violence is among the most
17 underreported crimes in the United States. So, as a
18 result, what we know about rape-related pregnancy is also
19 very limited. We know that reproductive coercion is sadly
20 a common experience. We know that through some of the
21 research, and we also know that from serving victims and
22 survivors through rape crisis centers. We know that
23 reproductive coercion happens far too often in adult
24 relationships, as well as in teen relationships.

25 Reproductive coercion includes acts and threats

1 that coerce a partner into having sex, trying to get a
2 partner pregnant without their consent, refusing to use or
3 removing contraception during sex, blocking a partner's
4 access to contraception or birth control. In the NISVS
5 study that I've already referenced found that of women who
6 are raped by an intimate partner, 30 percent of them had
7 experience reproductive coercion by that partner. And,
8 more specifically, 20 percent of those victims stated that
9 their partner tried to get them pregnant when they did not
10 want to become pregnant and blocked their access to birth
11 control, and 23 percent of victims reported that their
12 partner refused to use a condom.

13 So there are many reasons why sexual violence is
14 underreported. So much has to do with victims experiencing
15 shame and stigma that then gets intermixed with both their
16 experience of sexual violence and their need to seek
17 abortion. And so this drives many victims into the margins
18 of our communities. Many do not come forward, and many do
19 not identify as a victim due to fear for their safety, fear
20 that their privacy will be invaded if they openly share
21 what they've experienced. And we know these barriers can
22 be compounded for victims of color, immigrant victims, and
23 children due to systemic oppression and power imbalances in
24 our society.

25 So while the research is limited, we do know from

1 NISVS that approximately three million women in the U.S.
2 have become pregnant as a result of rape at some point in
3 their lives, and this crosses all racial and ethnic
4 boundaries. We also know from studies that early sexual
5 abuse is also associated with unwanted pregnancies and
6 abortion-seeking among teens and adult women. The United
7 Nations shows that the United States has higher rates of
8 adolescent pregnancy than many other industrialized
9 countries. In a study of over 1,000 women between the ages
10 of 18 and 22, it was found that 36 percent had been
11 sexually abused and 26 percent had become pregnant before
12 the age of 18. Sexual abuse and sexual coercion were
13 associated with those unwanted pregnancies.

14 In another study of over 13,000 American women
15 and girls ranging in age from 18 to 44, between the years
16 of 2011 and 2017 this study found that 6 percent of
17 participants were forced to have sex as their first sexual
18 experience, and the mean age of this experience for victims
19 was 15. And at the time, the coercive partner was six
20 years or more older than the victim. And 30 percent of
21 these participants in this study did have an unwanted
22 pregnancy as a result of this coercion with 24 percent of
23 them seeking abortion.

24 Another study in Washington State of over 500
25 young women found that two-thirds of them had become

1 pregnant after also being sexually abused as children. And
2 that abuse included molestation, attempted rape, and actual
3 rape, and these experiences were then linked with having
4 sex earlier, not using contraception, drug and alcohol
5 problems, homelessness, and engaging in survival sex for a
6 place to stay, as well as later physical or domestic
7 violence. So, again, we're seeing patterns here in the
8 research that child sexual abuse is linked to a whole host
9 of socioeconomic, medical, mental health issues and
10 struggles over a child's lifetime.

11 Finally, another study found that over 60 percent
12 of teen mothers had coercive sexual experiences, and 23
13 percent of them had become pregnant by the perpetrator.
14 Perpetrators in this study were most often family members.
15 Other perpetrators were boyfriends, dates, and friends.

16 Barbara and I wanted to share a bit about the
17 issue of consent and age disparity also. We feel that this
18 is also a really important part of our conversation today
19 as we're looking at legislation and best practices, and we
20 wanted to just clarify that not all children and teens who
21 are seeking abortions in Pennsylvania would be considered
22 victims of sexual violence because of the legal age of
23 consent, as well as definitions of child abuse and Child
24 Protective Services law.

25 So the age of consent in Pennsylvania, as you may

1 know, children aged 12 and under can never legally consent
2 to sexual activity. Teens between the ages of 13 and 15
3 are legally able to consent to sex with peers who are no
4 more than four years older than them. Teenagers who are 16
5 and older can consent to sexual activity.

6 And, you know, in addition to the conversation
7 about consent and also looking back at some of those
8 studies I just referenced, we also think it's important to
9 talk about age disparity within intimate relationships.

10 You may recall that some of those studies that linked
11 reproductive coercion and sexual violence with later
12 unwanted pregnancies found that there were age disparities
13 between the victim and the perpetrator. And we do know
14 from working with survivors, as well as the research, that
15 age disparities can create power imbalances and risk
16 factors for reproductive coercion, for sexual violence,
17 unwanted pregnancies, and then, later, abortion-seeking
18 behaviors.

19 We cannot stress enough that knowing the ages of
20 consent and also knowing the pervasiveness of child sexual
21 abuse in Pennsylvania, it is vital that children who are
22 reasonably suspected to be victims of sexual abuse be
23 referred to the systems that are designed to respond to
24 that abuse and to provide that comprehensive support that
25 is necessary for that child and that family.

1 Sorry, is there a -- I'm not sure if there was a
2 question or should I continue?

3 MAJORITY CHAIRWOMAN RAPP: No, continue.

4 MS. GRECO: Okay, thank you. I was just saying
5 that it's vital that children who are suspected to be
6 victims of child sexual abuse be referred to the
7 appropriate authorities, to ChildLine, and that they
8 receive the comprehensive services that they need and
9 deserve to heal from trauma and also the difficult
10 decisions that they face when that trauma results in an
11 unwanted pregnancy from that crime. Such services include
12 counseling and advocacy and many protective services at the
13 local level with rape crisis centers and partners in law
14 enforcement, the medical community, the advocacy centers,
15 and other service agencies that are in your local
16 districts.

17 At the same time, PCAR feels it's very important
18 that we also work together to move upstream and to invest
19 in prevention. When we look at those studies and when we
20 look at friends in our communities about, you know, healthy
21 relationships and reproductive coercion and unhealthy
22 relationships and the whole spectrum, we feel it's so
23 important that we're teaching our young Pennsylvanians, you
24 know, the importance of respect and healthy relationships
25 and healthy communication and consent and body autonomy and

1 gender equity and all of those important strategies that
2 the Centers for Disease Control promote to really stop
3 sexual violence from occurring in the first place. We feel
4 that is critical, simultaneously with making sure existing
5 victims are reported and receiving care.

6 We know that you know this. We know that the
7 work of this Committee is very much about trauma and about
8 making sure that our healthcare systems are best equipped
9 to help people across multiple forms of trauma, sexual
10 violence being one. We also know from the research and
11 from working with survivors that rape-related pregnancy is
12 also traumatic after surviving rape and incest. And so the
13 choices that these victims are facing in these situations
14 do not feel like choices at all to them, and they are
15 rather realities that they are forced to navigate where
16 none of the outcomes are ideal.

17 Some survivors do choose to carry a pregnancy to
18 full term, and they decide to keep that child and raise
19 that child. Others may pursue adoption options. Other
20 victims do choose to terminate a pregnancy that is a result
21 of the crime of rape. And we want you to know that trauma
22 encompasses all of these steps that a victim is seeking,
23 and this painful situation of course is further exacerbated
24 for children and teen victims due to where they are
25 developmentally, the limited power they have in our

1 society, and their limited understanding cognitively and
2 developmentally of what is happening and the complexities
3 of those choices and social systems, which really
4 underscores the importance of caring adults and supporting
5 those adults and supporting those children through this
6 traumatic experience.

7 We know that those supportive services can help
8 counteract the threats to a child's health over time that I
9 mentioned earlier in the research, and rape crisis centers
10 are just one of those critical resources that can help
11 children that are affected by sexual violence and in these
12 situations where they may be seeking reproductive
13 healthcare options.

14 We did hear from a rape crisis center who had
15 worked with a child who had become pregnant through the
16 rape by their uncle, and the rape crisis center worked with
17 the child and they worked with the family through the legal
18 process, and they also helped the child and the family
19 understand that full range of reproductive healthcare
20 options that were available. And the child did receive
21 abortion services. And the family and the child really
22 described that as being a critical component of their
23 healing from this rape that had been occurring for many
24 years by the uncle.

25 We also know that while these burdens are

1 extremely heavy the victims carry, they are not alone. We
2 are grateful at PCAR for the amazing work of rape crisis
3 centers locally, and they work with medical partners, they
4 work with child advocacy centers and other local service
5 providers to ensure that victims have the best available
6 support.

7 We wanted to conclude our remarks and summarize
8 leaving you with some recommendations for further
9 consideration. We feel strongly that medical care should
10 be expanded for victims of sexual violence, including
11 pediatric examiners. And I know Barbara with her expertise
12 can speak to that. We advocate to maintain access to
13 reproductive healthcare options for victims. We do support
14 victim-centered collaborations, and we know that victims
15 are best served when all those partners are working
16 together. We advocate that mandated reporter training is
17 provided across reproductive healthcare services and other
18 healthcare settings. PCAR and the local rape crisis center
19 network provides mandated reporter training to community
20 partners.

21 And finally, we wanted to ensure that we are
22 working together to invest in sexual violence prevention
23 and sex education, knowing if we can stop sexual violence
24 in the first place, we'll help protect these kids so that
25 they can thrive in their lives without carrying this

1 traumatic burden of both sexual violence, unwanted
2 pregnancy, and the need to seek abortion services.

3 So we thank you for your consideration and your
4 time, and we welcome your questions and recommendations.

5 MAJORITY CHAIRWOMAN RAPP: First of all, thank
6 you very much for your testimony. And I don't know if
7 you're aware, but one of the reasons that prompted me to
8 have the hearings was seeing from the abortion statistics
9 from the State of Pennsylvania was the number of little
10 girls who were receiving abortions in the State of
11 Pennsylvania.

12 And our first testifier in our series was from
13 the Department of Health, and when questioned about how is
14 the Department of Health following up, the response was
15 well, all the abortion facilities are mandated reporters if
16 there are children who are walking in their facilities
17 receiving abortion. But it was alarming to me seeing the
18 numbers of the 12 and under, 13-year-olds.

19 And I know that our Judiciary Committee has
20 looked at bills specifically on child and sex trafficking,
21 but I guess my question for you, knowing the background
22 now, is have you ever been contacted or the crisis centers
23 by abortion providers saying, hey, we just want you to know
24 we have a 12-year-old, an 11-year-old, 13-year-old, and we
25 believe that she needs to be referred to your center or

1 followed up by counseling? I just want to know what you've
2 experienced from any of the abortion providers themselves
3 because it didn't seem to be clear from some of our other
4 testifiers that that is actually happening, and we want it
5 to happen. And we want to make sure that these little
6 girls are actually being followed up and being provided the
7 services, especially through counseling, and some of the
8 services that you referred to.

9 MS. SHEAFFER: Thank you. I'd be happy to cover
10 that question. There have been -- although I'm not aware
11 of every referral in the local level between healthcare
12 providers and local rape crisis centers, but there have
13 been a few occasions on the State level when I've been
14 contacted by a healthcare provider and I was able to make a
15 referral to the local rape crisis center, so I know just a
16 little bit about that happening on the State level. But
17 what happens locally, you know, I may not always know
18 about.

19 I've also been involved with some trainings to
20 reproductive healthcare providers, and PCAR has partnered
21 with the Pennsylvania Coalition against Domestic Violence
22 on these trainings just to make sure the healthcare
23 providers are aware of services on the local level and
24 working collaboratively with them, so that is something we
25 have tried to do on the State level as well. Is that

1 helpful?

2 MAJORITY CHAIRWOMAN RAPP: Somewhat, but do you
3 have even one specific example where someone has actually
4 contacted you when a little girl came into a facility and
5 you were immediately contacted by that facility to say
6 please reach out to this county for this child for
7 counseling services or follow-up services?

8 MS. SHEAFFER: I can think of an example of that
9 where the healthcare provider was a nurse who had called
10 PCAR, got connected with me, and then I did make that
11 referral to the local -- I actually provided the
12 information, contact information to the healthcare provider
13 to contact rate crisis services.

14 MAJORITY CHAIRWOMAN RAPP: Thank you. I believe
15 Representative Frankel has a question.

16 DEMOCRATIC CHAIRMAN FRANKEL: Thank you, Madam
17 Chair, and thank you to both of you for the work you do in
18 our Commonwealth, so important given the level of sexual
19 violence that we see in our communities. A couple of
20 questions. You know, one, will a sexual assault nurse
21 conduct an exam if a child says a sexual encounter is
22 consensual?

23 MS. SHEAFFER: I'm an associate member of the
24 Pennsylvania chapter of the International Association of
25 Forensic Nurses. I work very closely with forensic nurses

1 across the Commonwealth. And I have always heard from
2 nurses and other healthcare professionals that if a child
3 or anyone of any age is refusing to get an exam, that they
4 would not force an exam on the patient. You know, there
5 are ways to talk about the situation and try to allay fears
6 or concerns that the patient may have, but they would not
7 want to force that kind of care upon a patient if they are,
8 you know, refusing or denying that a crime occurred.

9 DEMOCRATIC CHAIRMAN FRANKEL: Thank you. Do some
10 women who call and come in for counseling after a sexual
11 assault express fear that they could be pregnant, and what
12 counseling or referrals do you offer them under those
13 circumstances?

14 MS. SHEAFFER: These would be referrals primarily
15 that our local rape crisis network would be providing. And
16 what they would do if that's a concern, they can talk about
17 where they can receive a pregnancy test, whether that's the
18 person's healthcare provider or if there is a clinic in the
19 area, they can make those referrals. Many of our local
20 rape crisis centers work closely with other service
21 agencies within their regions. We encourage rape crisis
22 centers to make what we call a warm referral, you know,
23 that they know the provider and they can say to a client,
24 you know, I know so-and-so at this healthcare facility, and
25 they can help you get a pregnancy test, they can help talk

1 to you about steps and options. The rape crisis center
2 advocates themselves are educated on the options available,
3 and they can talk through all of those options with the
4 victim.

5 It's really important I think for victims to be
6 fully informed of those options. It can be really
7 difficult for a victim to, you know, think all these
8 options through and to consider what's best for them, but
9 it's incredibly important that they be making the best
10 decision they can for themselves. During a sexual assault
11 or rape, you know, power and control has been taken away
12 from the victim, and it's very important that they have a
13 full range of options so they can try to gain some of that
14 control back and some of that body autonomy back and be
15 able to take control and work on the healing process.

16 DEMOCRATIC CHAIRMAN FRANKEL: Thanks. And do you
17 see women who are victims of sexual assault encounter
18 barriers to accessing abortion care based on financial
19 concerns, lack of providers nearby, lack of childcare, paid
20 leave, or other barriers?

21 MS. SHEAFFER: I actually have, and, you know, a
22 lot of my experience is through the advocates. I mean, now
23 occasionally, you know, we might get a call from a victim
24 or a victim's parent, but many times my connection is
25 through an advocate working directly with the victim. I

1 have definitely heard of concerns around cost and also
2 distance to travel for an abortion if that is the decision
3 they have made for themselves. Those are definitely
4 factors I have heard of.

5 Another issue that I think is really important to
6 understand is that this is -- you know, overcoming the
7 trauma from a sexual assault is extremely difficult and
8 takes a lot of time. And dealing with the shock of a
9 sexual assault or rape can be -- I mean, it's traumatic.
10 It's a very traumatic experience, and it can be very hard
11 to process what has happened to somebody. And what I have
12 seen over the many years I've worked in this field is that
13 a victim --

14 MAJORITY CHAIRWOMAN RAPP: If you could just --

15 MS. SHEAFFER: I'm sorry. I think somehow I got
16 muted, and I apologize.

17 MAJORITY CHAIRWOMAN RAPP: We have you back.

18 MS. SHEAFFER: Okay.

19 DEMOCRATIC CHAIRMAN FRANKEL: We lost about 30
20 seconds of your response.

21 MS. SHEAFFER: Oh, okay. So, yes, I just wanted
22 to emphasize the trauma that a victim experiences after a
23 sexual assault is extremely intense, regardless of the
24 situation. And often, as we know, the vast majority of
25 victims are victimized by people they know and people they

1 trust, so there's another layer of shock and trauma to
2 overcome.

3 And what I have experienced again through
4 advocates or directly from victims that may have called
5 PCAR is that it might take a period of time until they
6 realize they are pregnant or maybe even be able to mentally
7 come to terms with the fact that they are pregnant. And
8 what I have experienced is I am being contacted when they
9 are really approaching the limited, you know, time frame in
10 which they can get an abortion, and it becomes a scramble
11 financially, emotionally, and mentally to try to figure out
12 the processes because it can take quite a while to come to
13 terms with what the reality is, and then they need to make
14 a decision.

15 DEMOCRATIC CHAIRMAN FRANKEL: Thank you very
16 much.

17 MAJORITY CHAIRWOMAN RAPP: Thank you,
18 Representative. Representative Twardzik.

19 REPRESENTATIVE TWARDZIK: Yes, good morning.
20 Thank you for coming out. It's very informative.

21 But, as an organization, how do you help educate
22 children on sexual violence and the tools they can use to
23 identify and prevent it?

24 MS. SHEAFFER: Sure. We work with our local rape
25 crisis centers to be providing that education, and I think

1 any additional support, as Donna was talking about, you
2 know, working on the upstream end of this is incredibly
3 important, so local rape crisis centers do provide
4 prevention education within schools, and additional support
5 for that I think would be incredibly important.

6 We also have resources to educate parents and
7 family members around sexual assault and abuse and
8 prevention. One of the examples of this is called Parents
9 in the Know, and it's to help educate and inform parents
10 and help them protect children and, you know, work within
11 their communities to do so. So there's a variety of
12 education and resources that happen on the local level.

13 REPRESENTATIVE TWARDZIK: Okay. Thank you very
14 much. What is your most successful program, do you think?

15 MS. SHEAFFER: That should probably be answered
16 by a prevention educator. I personally am a fan of the
17 Parents in the Know curriculum because I think it's so
18 valuable, but that is something we probably should get back
19 to you on more definitively from our prevention department.

20 REPRESENTATIVE TWARDZIK: Okay. Thank you very
21 much.

22 MS. GRECO: There are a range of prevention
23 strategies, as Barbara said, and we know, you know,
24 effective prevention really requires, you know, programs
25 and strategies to be tailored to the specific needs of the

1 community. But, as Barbara mentioned, Parents in the Know,
2 there's another curriculum that we use that's called One
3 Caring Adult, and we know that to best protect children
4 from child sexual abuse, we need to engage adults in their
5 lives, whether it's school teachers, parents, faith
6 leaders, coaches, you know, wherever the child is
7 interacting we also need to make sure that those adults
8 that are in their lives have the tools to support the
9 child, identify child sexual abuse, report it.

10 But much of the early work we do with kids is,
11 you know, around respect and choices and consent, and we
12 were excited to be developing Safe Secure Kids, which is
13 another new strategy to help throughout Pennsylvania with
14 preventing child sexual abuse. But we would be so grateful
15 to send the Committee additional links to the specific
16 strategies that PCAR and the network of rape crisis centers
17 are using, and we really appreciate that question about
18 prevention.

19 REPRESENTATIVE TWARDZIK: Well, thank you very
20 much. I appreciate that. Again, I was involved with
21 Catholic school boards, so I went through Protecting God's
22 Children plan, so the more education we get out, obviously,
23 hopefully, the more troubles we can solve. Thank you.

24 MS. GRECO: Thank you.

25 MAJORITY CHAIRWOMAN RAPP: Thank you,

1 Representative. I believe we have a question from
2 Representative Lewis, who is with us virtually. Oh, I'm
3 sorry, Representative Lewis.

4 REPRESENTATIVE LEWIS: Thank you, Madam Chair.
5 I'm here. I'm here. It's not a hologram. I am here.

6 MAJORITY CHAIRWOMAN RAPP: The invisible man. Go
7 ahead --

8 REPRESENTATIVE LEWIS: Thank you.

9 MAJORITY CHAIRWOMAN RAPP: -- Representative.

10 REPRESENTATIVE LEWIS: Well, thank you both so
11 much for your testimony today and for everything you do to
12 advocate on behalf of victims.

13 I want to talk a little bit about reporting
14 requirements and red flags and then recommended best
15 practices moving forward. This is something we've talking
16 about throughout these hearings, and I've been really blown
17 away by the statistics showing that as many as almost a
18 dozen girls 12 and under every single year are going to
19 seek abortions, which clearly is an indication that these
20 are victims of horrific crimes.

21 And my question to you is, first, can you talk a
22 little bit about the educational aspect between you and
23 healthcare providers as far as what are the current
24 reporting requirements when a child comes in and even
25 somebody 13, 14, and 15, and you talked about the age of

1 consent, but say there's a reoccurring situation where
2 someone is coming in for their second or third abortion,
3 what is the current I guess you could say requirement and
4 then couple that with best practice of reporting that to a
5 crisis center or to a law enforcement agency?

6 MS. GRECO: Thank you for that question. I can
7 start responding to that. Just given what we know about
8 the age of consent and Child Protective Services law
9 requirements, you know, healthcare providers are considered
10 mandated reporters, as you know, so if they have reason to
11 suspect that a child coming before them is a victim of
12 abuse based on their training and just the suspicion that
13 the child is a victim, they are required to make a report
14 to ChildLine, to Child Protective Services, and --

15 REPRESENTATIVE LEWIS: I --

16 MS. GRECO: Oh, I'm sorry.

17 REPRESENTATIVE LEWIS: Go ahead. Go ahead.
18 Continue.

19 MS. GRECO: Yes. And we would hope that, you
20 know, after that report is made that, you know, referrals
21 to helpful services like rape crisis centers are made.
22 However, we would not be the first point of contact. Of
23 course, if there is a child that's being sexually abused,
24 and, as you mentioned, children 12 and under legally cannot
25 consent, so they could be viewed as victims, that report

1 should be made to ChildLine, and we would hope that through
2 the investigation process, you know, services are wrapped
3 around that child and their loved ones, including rape
4 crisis centers but also other important victim service
5 providers.

6 REPRESENTATIVE LEWIS: Thank you. Yesterday, we
7 kind of were asking a care provider about this, a
8 healthcare provider, and there seemed to be a similar
9 response, only this individual kind of said, look, we would
10 investigate. And to me, if a 12-year-old comes in, no
11 investigation is necessary. Clearly, it's a victim of a
12 crime, done, like there's a mandatory report that must take
13 place. I wonder and I'm curious what are your opinions on
14 this? If there's a 12-year-old that comes in, should there
15 not be a presumption that that individual is clearly a
16 victim and therefore the mandatory report must take place?

17 MS. GRECO: Yes, I appreciate that, and I wonder
18 if that response was rooted in, you know, just trying to
19 provide the best services possible and not wanting to
20 alienate children from seeking the care they need, but I
21 think that our opinion at PCAR would be that if, again,
22 there's a reasonable cause to suspect that the child coming
23 before them is a victim based on their age, based on the
24 definitions of Child Protective Services of abuse, then
25 they would be obligated to make that report. Of course,

1 through the investigation process that ChildLine or Child
2 Protective Services does, they may find that, you know,
3 additional services and resources are helpful to that child
4 and that family.

5 But PCAR in our training when we're doing
6 mandated reporter training, we really emphasize to mandated
7 reporters that they are not required to investigate fully
8 before making a report. That is left for Child Protective
9 Services and law enforcement, but that their duty by law
10 through their training is to make that report if they
11 suspect that the child is a victim. I hope that helps to
12 clarify.

13 REPRESENTATIVE LEWIS: It does. Can you talk
14 just with your expertise and experience in this field kind
15 of some of the red flags that a healthcare -- and, by the
16 way, when I say healthcare, I'm talking about every other
17 care. I do not consider abortion care in any capacity -- I
18 believe it's taking of a life, so just let the record
19 reflect, healthcare to me is the other healthcare where
20 you're providing care for somebody. But what type of
21 education could be provided to healthcare providers in the
22 context of identifying red flags that potentially someone
23 seeking an abortion is the victim of sex trafficking or
24 some other type of abuse? What are some red flags you
25 would say with training that could be required?

1 MS. SHEAFFER: I can talk about this a bit. I
2 mean, some red flags might be just, you know, if there's --
3 and again, you know, what's to be reported if there's
4 reasonable cause to suspect, so, you know, say there's
5 other injuries on the patient, you know, it looks like
6 there's, you know, bruising, abuse, you know, something
7 else might be going on, that might be -- I mean, certainly
8 if you have bruising or injury on a child, you can suspect
9 I would say child abuse, so that should be reported.

10 From what we know around trafficking, there can
11 be things like, you know, certain tattoos and what a tattoo
12 might look like on different parts of the body, that might
13 be an indicator, which would bode some questions, I mean,
14 especially, if it's a younger child with tattoos, you know,
15 questions around where that may have come from or what that
16 is. I mean, my understanding is that I'm not sure what age
17 you can legally get a tattoo. I think it might be 18. I
18 don't know if parent consent is allowed for that at a
19 younger age, but that could be an indicator. Perhaps who
20 came with the patient, you know, does it look like there's
21 some kind of issue within the relationship? Is the person
22 or partner with the patient someone who appears to be in
23 control and making decisions for that person, not letting
24 them speak for themselves and not being willing to leave
25 the room during any procedures or healthcare history

1 questions. So I think there are a variety of issues or
2 indicators that might cause a provider to, you know,
3 reasonably suspect that there might be some abuse going on
4 and that it would be reported under the law.

5 REPRESENTATIVE LEWIS: Thank you. Thank you.
6 And that does help clarify, and I appreciate the answers
7 from both of you. Thank you, Madam Chair.

8 MAJORITY CHAIRWOMAN RAPP: Thank you,
9 Representative Lewis. Representative Hershey.

10 REPRESENTATIVE HERSHEY: I actually waive off.
11 The good gentleman from Dauphin County covered my
12 questions. Thanks.

13 MAJORITY CHAIRWOMAN RAPP: Representative
14 Schemel.

15 REPRESENTATIVE SCHEMEL: Thank you, Madam Chair,
16 and thank you, ladies, for your testimony.

17 Just following a little bit off of the last
18 questioner's questions, so a provider in a facility, you
19 know, if a woman presents as pregnant at a doctor's office
20 or I say a girl and she's a minor, you know, what sorts of
21 things -- sort of walk me through what you would recommend
22 that a provider would be looking for, what kind of
23 questions or examination would you recommend that they do,
24 you know, given the limitations that they might have?

25 MS. SHEAFFER: Well, I want do make it clear that

1 I do not have a medical or healthcare background, so, you
2 know, I can't speak directly for what a provider would do.
3 I mean, there are screening questions that could be asked,
4 you know, just about, you know, what brings them into the
5 office today, how are they doing, how is their health.
6 There are screening questions that could be asked around
7 domestic violence and sexual violence to see if this might
8 be an issue or a factor that they are dealing with, and
9 then referrals should be made. You know, I think some
10 general healthcare questions and screenings around that can
11 be helpful.

12 And it's important to note I think that, you
13 know, not everyone might feel safe in divulging information
14 even to a healthcare provider, and it may not be something
15 that a patient may divulge or provide information on during
16 visits or that first, you know, second, third visit. I
17 mean, what's important--and I think healthcare really works
18 to develop rapport with their patients, which can be very
19 difficult in a very busy office when you're serving many
20 patients over very short amounts of time that we have in
21 our healthcare system. But I think there are general
22 screening questions that can be asked and things that can
23 be considered for healthcare.

24 And we do encourage, again, as we mentioned on
25 the local level, that rape crisis centers be connecting and

1 providing education and warm referrals to and from
2 healthcare offices and services.

3 REPRESENTATIVE SCHEMEL: Okay, thanks. And
4 actually that leads into my next question. You talk about
5 the warm handoff, which I certainly can understand,
6 particularly, you know, in the case of someone who was a
7 victim of rape. Yesterday, we heard testimony from some
8 such centers. We heard testimony from a Planned Parenthood
9 center. We also heard testimony from a crisis pregnancy
10 center that is non-abortive. Earlier in the testimony of
11 yours or Ms. Greco's, there was a reference to, you know,
12 women and girls who have been the victims of rape, you
13 know, choosing all options. You know, some choose
14 abortion, some choose to bring their children to term. So
15 do you have relationships with organizations like Planned
16 Parenthood, as well as non-abortive agencies like a crisis
17 pregnancy center? And do you refer to both of those?

18 MS. SHEAFFER: Absolutely. We would expect the
19 local rape crisis centers to do that. I mean, that is part
20 of the full range of services. And if that is, you know,
21 the option that a survivor chooses, then that's important
22 to support, absolutely. I know that rape crisis centers
23 will list varieties of services for reproductive healthcare
24 and have seen on those lists crisis pregnancy services
25 listed. I have visited those centers as part of my work as

1 well, so, yes, it's part of that range of options that
2 victims should have access to.

3 REPRESENTATIVE SCHEMEL: Okay, great. And then
4 one final question along the same line, in the work that
5 you do since you provide the warm handoff and you also
6 explained in your testimony that you often involve other
7 people that are involved in these girls' lives, parents,
8 partners, faith leaders, and so forth, are you ever
9 concerned about coercive abortions where the young girl may
10 be being coerced into a decision to abort her child?

11 MS. SHEAFFER: And again, I mean, I want to
12 emphasize that this is what's happening on the local level,
13 you know, not -- as someone representing PCAR, I'm usually
14 not working directly with victims themselves. That's what
15 our rape crisis centers are doing.

16 I mean, again, it goes back to that empowering
17 victims and allowing them to choose the option that is best
18 for them. You know, as I was saying earlier, a forced
19 forensic exam is not appropriate and should not be done, so
20 anything forced upon a victim is wrong and should not be
21 done either. It's very important to support the victim and
22 what they wish for themselves. That is what we support
23 rape crisis centers to do, you know, in their work.

24 And advocates can often serve sort of like the
25 liaison between the victim and parents or, you know, the

1 victim and family members. Family members also need
2 support, and that is something rape crisis centers do. You
3 know, when sexual violence occurs within a family,
4 obviously, it directly affects the person who's been
5 victimized, but that can have a major effect on the entire
6 family, of course, so those services are available to them.
7 But again, I mean, the advocate really is there to support
8 the victim and what they wish, and we would not want
9 anything forced upon somebody. I mean, they already had
10 something forced upon them, so we would not want something
11 in addition being forced upon them.

12 REPRESENTATIVE SCHEMEL: Very good. Thank you so
13 much.

14 MAJORITY CHAIRWOMAN RAPP: Thank you,
15 Representative. And our last question for you comes from
16 Representative Owlett, and he is virtual, so,
17 Representative Owlett, if you want to ask your question,
18 please.

19 REPRESENTATIVE OWLETT: Thank you, Madam Chair.

20 Just real briefly, and I was thinking about this
21 as you were testifying and I was remembering House Bill 156
22 that we worked on that you guys wrote a letter of support
23 for, which I really appreciated. This is the tender years
24 bill. These are crimes that we're talking about, and a
25 number of these young gals have gone through unbelievably

1 traumatic experiences. And our crisis pregnancy centers
2 and child advocacy centers, you know, are really a great
3 asset to try to dig down and figure out how this is
4 happening, where it's happening, and really hold those
5 accountable that are committing these crimes.

6 Talk a little bit about why this is so important
7 and even the next steps in continuing to protect these
8 young gals taking that from 13 to 16 because it didn't get
9 a unanimous vote. We did have people that voted no against
10 it. There were 29 no votes. And to me it just seems like
11 if we're going to talk about this, we also to talk about
12 how we can help those gals in the next step, especially
13 those that are in those really challenging years of 13 to
14 16 where it could be happening over and over again. If you
15 wouldn't mind just giving us a quick, you know, why you
16 support that and why you think it's important.

17 MS. GRECO: Sure, and thank you for your
18 leadership on that bill, Representative. We did join the
19 Pennsylvania District Attorneys Association in circulating
20 that letter and were grateful to work with them on the
21 bill.

22 With the tender years, you know, it really
23 enables additional evidence to come into prosecution and,
24 you know, what we were talking about in our testimony
25 related to the underreported nature of sexual violence and

1 how hard it is for children especially to disclose what's
2 happening to them. And we do know when they do tell
3 someone, it is usually someone that they trust and someone
4 that's close to them in their lives. And those types of
5 statements we feel are so important to be allowable, which
6 the tender years doctrine speaks to. And so we do feel
7 that that is an important bill and will continue to
8 advocate and help discuss that with Members and just
9 grateful for your leadership on it. I hope that's helpful.

10 REPRESENTATIVE OWLETT: Yes, I appreciate it.
11 It's important. We have to help in all aspects, and this
12 is one way that we can. I appreciate your support and look
13 forward to hopefully getting a vote in the Senate, so thank
14 you.

15 MAJORITY CHAIRWOMAN RAPP: Thank you,
16 Representative.

17 And Ms. Sheaffer and Ms. Greco, I truly thank
18 you. This was very, very informative, and thank you for
19 your written testimony. We appreciate you taking the time
20 out of your day to be with us.

21 Representative Frankel, did you have any other
22 remarks, sir?

23 DEMOCRATIC CHAIRMAN FRANKEL: I believe this was
24 a very valuable hearing from both of you, and thank you for
25 testifying today.

1 MAJORITY CHAIRWOMAN RAPP: Thank you.

2 MS. GRECO: Thank you all very much.

3 MS. SHEAFFER: Thank you.

4 MAJORITY CHAIRWOMAN RAPP: Next, we have a panel
5 of testifiers who are parents of children or young adults
6 with Down syndrome, and we have Jessica -- I apologize if I
7 mispronounce your names -- Capitani --

8 MS. CAPITANI: Capitani.

9 MAJORITY CHAIRWOMAN RAPP: -- and David Perry and
10 Kurt Kondrich, who is the parent of Chloe Kondrich. Are
11 you all here?

12 MS. CAPITANI: Yes.

13 MAJORITY CHAIRWOMAN RAPP: Oh, is David? Okay.

14 MR. KONDRICH: Yes, we're here.

15 MAJORITY CHAIRWOMAN RAPP: As testifiers, if you
16 would please raise your right hand.

17

18 (Witnesses sworn.)

19

20 MAJORITY CHAIRWOMAN RAPP: Thank you. And we
21 will start with Jessica if you don't mind me calling you by
22 your first name. you may proceed.

23 MS. CAPITANI: Good morning, and thank you to
24 Committee Chairwoman Rapp, Chairman Frankel, and Committee
25 Members for holding this hearing and allowing me to share

1 my testimony today. My name is Jessica Capitani, and I'm a
2 resident of Dauphin County. I graduated from the
3 University of Virginia with a degree in psychology and
4 currently I'm a stay-at-home mom. My husband Frank is a
5 civil engineer with degrees from Gettysburg College and
6 Penn State, and our only child Caden, he's 15, and has Down
7 syndrome.

8 As someone who has actually experienced receiving
9 a definitive prenatal diagnosis of Down syndrome for my
10 child, I'd like to share my experience with you today. And
11 bear with me because it is difficult and painful to
12 revisit, but it's important.

13 When I was halfway through my first and only
14 pregnancy, I received the standard 20-week ultrasound that
15 can reveal the baby's gender. Our excitement, however, was
16 shattered when the doctor shared his suspicion of a
17 chromosomal abnormality and said it was time for an
18 amniocentesis. I had previously declined testing but
19 reluctantly agreed. And 10 long days later, he called me
20 at home with results. "I'm sorry," he began. "I know this
21 isn't what anyone wants to hear, but your baby is a girl.
22 I recommend scheduling an abortion as soon as possible
23 since you only have two weeks left by law before you're too
24 far along to receive one. As you consider quality-of-life
25 issues, keep in mind that females are more likely to suffer

1 from certain diseases like breast cancer and autoimmune
2 disorders. They're less likely to achieve the career and
3 financial status of a male, and they're more likely to be
4 victims of abuse and discrimination."

5 Of course, this is not what happened because that
6 would be offensive. Doctors don't have this conversation
7 because of an X chromosome, but they do have it because of
8 an extra 21st chromosome, also known as trisomy 21 or Down
9 syndrome. So by substituting Down syndrome for being
10 female, that will provide an idea of how Caden's prenatal
11 diagnosis was delivered to me, and it is still offensive.

12 I was informed about every possible medical
13 condition and negative outcome that might be associated, no
14 matter how unlikely and without context. I was warned of
15 perceived burdens and expenses, and the phrase quality-of-
16 life was repeated often. I was not given information on
17 early intervention, Medicaid, positive outcomes,
18 protections like ADA and IDEA, or even a connection to a
19 family raising a child with Down syndrome.

20 In retrospect, the expectation that was placed in
21 my mind about life raising this child was so far from our
22 actuality today that it would be laughable if it weren't so
23 egregious. I believed the narrative that this discussion
24 was between a woman and her doctor, but I had only met the
25 doctor twice before the ultrasound. He knew nothing about

1 our lives or marriage and couldn't answer general
2 disability questions I had about things like special
3 education or social services. In fact, when I asked what
4 type of Down syndrome my son had, my doctor said, well,
5 what do you mean? He wasn't even aware that there are
6 three types of trisomy 21. And he was not a doctor without
7 merit. He was the head of the obstetrics/gynecology
8 department at our hospital and had taught at an Ivy League
9 medical school.

10 I felt that he wanted to clear my conscience
11 about abortion. He began to refer to our unborn baby as
12 "it" though we had already chosen names. He said it was a
13 responsible choice to avoid a life of suffering as if
14 suffering were a given, and gone were the offers to hear
15 the heartbeat. I became pregnant with a medical condition
16 instead of a child.

17 We had tried to conceive this baby for nearly two
18 years. He was wanted and loved from the moment I knew I
19 was pregnant. I was tortured by this decision not because
20 of the diagnosis but because of the pressure to abort a
21 baby that I loved. I cannot overstate the trauma and hurt
22 I experienced as a pregnant woman having anyone suggest my
23 unborn son was better off aborted, much less from medical
24 professionals I was supposed to trust to treat both of us.
25 I didn't want to give up on my baby. I could feel Caden's

1 kicks and hiccups even as I considered his fate.

2 As the abortion clock ticked, I told my doctor
3 that I didn't know what I should do. He replied that 75
4 percent of Down syndrome pregnancies at his clinic were
5 aborted. However, that number would be even higher without
6 the local Amish community, who keep their babies.

7 Since I was still wavering, my doctor's staff
8 scheduled my appointment with the abortion provider as a
9 courtesy so I wouldn't miss the drop-dead date. It was
10 clear that the default position was abortion, and the
11 pressure to comply was enormous.

12 My doctor described the procedure of a late
13 second trimester abortion. There would be an injection
14 into my womb that would kill the baby, and then two to
15 three days later, I would drive to Philadelphia to deliver
16 my dead baby, who I would know would only be dead because I
17 as his mother had rejected his diagnosis of Down syndrome.
18 I was filled with unbearable shame at the lengths to which
19 we might be willing to go to rid ourselves of this
20 diagnosis.

21 A study published in the February 2021 issue of
22 *Health Affairs*, a health policy journal, surveyed 714
23 physicians in various specialties and locations on their
24 feelings about people with disabilities. Four-fifths of
25 physicians felt that people with disabilities have a lower

1 quality of life, and only 40 percent felt that they could
2 provide the same standard of care to the disabled that they
3 do to others. It isn't hard to understand then how most
4 babies prenatally diagnosed with Down syndrome end up
5 aborted considering this overwhelming bias on the part of
6 physicians.

7 I felt rushed and too ill-informed about Down
8 syndrome to make a decision, so I researched on my own. I
9 discovered that information about Down syndrome is often
10 outdated, overly negative, or even false. The Pennsylvania
11 Department of Health's website at the time was itself full
12 of inaccuracies. For example, it stated that people with
13 Down syndrome fail to read. Ironically, I have a video of
14 Caden, who started reading at age 3, reading that exact
15 statement. Though the information on the website was
16 finally updated three years ago after much prodding, I
17 remain shocked that such archaic information was presented
18 on any health website so very recently. It begs the
19 question of just how much of the scant information that a
20 woman might receive after a prenatal diagnosis is flawed.

21 One of the most powerful discoveries in my
22 personal research was that there was a waiting list of
23 people to adopt a baby with Down syndrome. At the time, it
24 was 150 families long. I could not reconcile the existence
25 of this waiting list, much less its sheer length, with how

1 undesirable parenting a child with Down syndrome had been
2 presented to me. I wondered what do these people know
3 about Down syndrome that I did not, and it challenged me to
4 search beyond what I was being told.

5 I joined various online chatrooms to learn from
6 the real experts, families raising a child with Down
7 syndrome, and they seemed like normal families with loving
8 and raising their disabled child like any other. I learned
9 that individuals with Down syndrome were smashing barriers
10 at a greater rate than ever before. They're going to
11 college, living independently, working, and getting
12 married. Indeed, there has never been a greater time to be
13 born with Down syndrome. And yet, there has never been a
14 time with greater threat to being born with Down syndrome.

15 Today, I proudly defend the value of Caden's life
16 as equal to any other, but as a pro-choice supporter, it
17 became difficult for me to assert the absolute value of his
18 life while simultaneously conceding that anyone should be
19 able to decide if his life met their threshold of
20 worthiness. That is blatant ableism. Ableism is rooted in
21 the bigoted belief that people with disabilities are
22 inferior, and it promotes attitudes that devalue and limit
23 the potential of the disabled. Aborting a baby that was
24 wanted until it was diagnosed with Down syndrome is the
25 epitome of that prejudice. I was being counseled to

1 calculate the cost and benefits of another human being
2 relative to my own personal sliding scale as if I were
3 weighing fruit at the market instead of a life. The
4 hypocrisy became too great for me to defend. Caden's
5 innate dignity as a person is not dependent on anyone
6 else's whim. Either Down syndrome is a life worth living
7 or it isn't.

8 The Down Syndrome Protection Act no more forces
9 anyone to have a baby with Down syndrome than our current
10 law forces anyone to have a girl. If that were the case,
11 then only boys would be allowed to be aborted. This bill
12 does not make childbirth mandatory. If a woman had no
13 means to support or didn't want another child or for
14 countless other reasons, the law would not remove abortion
15 as an option.

16 As a disability rights advocate, I am keenly
17 aware of the need for increased disability services, but
18 the way to solve that need is not to prevent people with
19 Down syndrome from being born at all. Suggesting their
20 existence is contingent on money is despicable. It's hard
21 to imagine another population for which that would be
22 considered a solution. We as a society stress the values
23 of diversity and inclusion, and it is disingenuous to fight
24 disability discrimination in the community while condoning
25 discrimination at the very diagnosis of that disability. A

1 prenatal diagnosis is not a free pass to justify ableism,
2 and turning a blind eye to that harms every individual
3 currently living with Down syndrome who will bear the
4 burden of perpetuating that stigma. The Down Syndrome
5 Protection Act promotes the inherent worth in all of us.

6 Thank you so much for allowing me to share my
7 testimony today.

8 MAJORITY CHAIRWOMAN RAPP: Thank you, Jessica,
9 and I hope that you will stay with us. And we have two
10 more parents to testify before we will have questions if
11 you could stay with us.

12 MS. CAPITANI: Thank you.

13 MAJORITY CHAIRWOMAN RAPP: So our next parent to
14 offer testimony is David Perry. David, are you with us? I
15 believe you have yourself muted. There you go.

16 MR. PERRY: You're correct, thank you.

17 Thanks so much to the Committee for having these
18 hearings and for having me here.

19 I'm the father of a 14-year-old boy with Down
20 syndrome. He's a brilliant young man with a beard on his
21 chin, and I really don't know where the time goes. I was
22 thinking about the first time I held him in my arms, which
23 I remember very clearly.

24 He's an amazing kid. He's nonspeaking, he's
25 autistic, he's musical, he's athletic, and he's quite

1 simply the light of my life. And I'm here speaking today
2 because I am resolutely dedicated to building a better
3 future for him and building a world that's more inclusive
4 for people with Down syndrome, for people with disabilities
5 of all sorts.

6 And as a historian, which I am, I'm deeply aware
7 of the history of disability discrimination in this country
8 and around the world, and I'm concerned about a future in
9 which Down syndrome disappears.

10 But the best way I believe to prevent abortions
11 after a prenatal diagnosis is to make the words "Down
12 syndrome" less scary. And these bills that criminalize
13 abortion after a prenatal diagnosis impose a specter of
14 criminal penalties between a pregnant individual and their
15 doctor, making it harder to reach people right at their
16 most vulnerable moments.

17 Now, we know and we've heard that far too often
18 when people hear these words Down syndrome in this first
19 moment, it's easy to spiral into pathways laced with
20 misinformation. Sometimes you're just handed
21 misinformation and fear. And I remember that fear. I know
22 that fear that comes from ignorance and from stigma. I
23 know what it feels like. And I believe that the antidote
24 to that fear is truth.

25 And so in the Down syndrome community, as a

1 response to this problem, we developed the pro-information
2 movement. It's really a truly remarkable bipartisan
3 coalition from people on all sides of the abortion issue.
4 We have very different ideas about abortion and
5 reproductive rights, but we came together to form the pro-
6 information movement to make sure that every single
7 pregnant person would get the best possible information
8 following a prenatal diagnosis.

9 And I'm just not sure -- I hope everyone
10 understands I'm not sure there's not been another movement
11 like this in terms of the people that brought together, the
12 coalition we built. And I'm sorry to say that the kinds of
13 criminalization bills that we're discussing today have
14 destroyed that coalition. It sets us against each other,
15 and it doesn't actually help support people who, with much
16 better information, with more care, more truth, might
17 choose to keep a pregnancy after a prenatal diagnosis.

18 These criminalization bills use Down syndrome to
19 drive wedges between us, to polarize. And I believe that
20 if what you really want to do is lower abortion rates
21 following a prenatal diagnosis, then I urge you to look
22 back at the Pennsylvania's pro-information law that you
23 passed in 2014. I have to tell you that law is
24 insufficient. I've read the three-page pamphlet. It is
25 still, as we just heard, a list of medical risk factors

1 with very minimal -- you know, maybe a sentence or two
2 about early intervention. It has a couple of little
3 resources, but it is a document of risk. It is dry. It is
4 not going to solve this problem. I think you can do
5 better. I urge you instead to use your time to go back to
6 that law and make sure the information you provide is
7 robust, accessible, informative, and compelling.

8 We also know that many pregnant individuals
9 terminate pregnancies after a prenatal diagnosis because
10 they believe they cannot afford to raise a child with Down
11 syndrome. And again, we've heard about how that
12 information is presented. And you have the chance to fix
13 that, too, by better funding special education, healthcare,
14 respite care, and all the other support services that our
15 community needs and especially -- and this is really
16 important -- making sure that those supports are easy to
17 access without massive administrative burdens because I can
18 tell you even when the supports are there, the access
19 systems are broken.

20 In order to qualify for supports and services,
21 whether through Medicaid or the schools, early
22 intervention, the interlaced local, Federal, and State
23 programs that really can help parents and families like
24 mine so much, we have to talk about suffering. The way to
25 access supports is to talk about suffering. I can't get

1 support for my son unless I tell the State about his worst
2 day, about how bad things are. I cannot get support if I
3 talk about how happy we are.

4 So lawmakers -- and this is true around the
5 country at all levels of government -- have created systems
6 in which parents like me are forced to talk about struggle.
7 And so the narrative about Down syndrome, about all of
8 these disability systems is one of struggle and hardship.
9 And you can fix that. You can fix that so we can talk
10 about strength and success and joy.

11 These are arenas in which we can and have
12 genuinely worked together across the aisle, across our
13 divides and actually make the world a more inclusive place
14 where we can add more information rather than using
15 criminalization to create silences at exactly the moment
16 where we need more speech. Because, every day, people with
17 Down syndrome are exceeding the boundaries of what we
18 thought possible, whether in education or jobs or personal
19 lives or contributions to the community or just happiness.
20 Every day, my son Nico surprises me, and all of our efforts
21 should be focused on expanding opportunities, expanding
22 supports, and telling these stories. Thank you very much.

23 MAJORITY CHAIRWOMAN RAPP: Thank you, David. And
24 our next testifier for the panel is Kurt Kondrich and his
25 daughter Chloe. You may proceed.

1 MR. KONDRICH: Are you able to hear us?

2 MAJORITY CHAIRWOMAN RAPP: Yes.

3 MR. KONDRICH: Okay. Hold on. I think I'm
4 getting feedback.

5 MS. METZLER: Kurt, are you on both phone and the
6 computer?

7 MR. KONDRICH: Yes.

8 MS. METZLER: Okay. You have to keep one of them
9 muted so -- there you go.

10 MAJORITY CHAIRWOMAN RAPP: Sorry, we can't hear
11 you, Kurt. Kurt, we're unable to hear you.

12 MR. KONDRICH: Do I have to hit some unmute
13 thing? I'm sorry. It's terrible.

14 MS. KONDRICH: Oh, my goodness.

15 MR. KONDRICH: I'm going to hang up my phone.
16 Okay. You can hear us now, correct?

17 MS. METZLER: Correct.

18 MAJORITY CHAIRWOMAN RAPP: Yes, that's much
19 better.

20 MR. KONDRICH: Yes, I cannot hear you, but I
21 think we're clear now. Our phone was only working --

22 MS. KONDRICH: What happened?

23 MR. KONDRICH: Our phone was only working to hear
24 things, so we're going to go ahead and testify without
25 being able to hear you. So this is my daughter Chloe, and

1 we're here today to testify. I want to thank
2 Representative Rapp, Representative Frankel. I want to
3 thank Jessica and David for your powerful testimony. And I
4 have some visuals I wanted to share with you. I'll try to
5 make this as quick as possible. Thank you again. We would
6 have loved to have been there in person. And we've met
7 many of you over the years with our advocacy at the
8 Capitol.

9 So, Chloe, if you could read this real quick.

10 MS. KONDRICH: To who?

11 MR. KONDRICH: To the people out there.

12 MS. KONDRICH: I can't see them.

13 MR. KONDRICH: They're right there. Go ahead and
14 read to them. Go ahead.

15 MS. KONDRICH: I can't hear them.

16 MR. KONDRICH: You can hear them. Go ahead. Go
17 ahead.

18 MS. KONDRICH: [inaudible]?

19 MR. KONDRICH: Yes, go ahead. It's on now, so
20 you can read to them. Go ahead.

21 MS. KONDRICH: I can't see them.

22 MR. KONDRICH: Okay. Go ahead, sweetie.

23 MS. KONDRICH: I can't see them.

24 MR. KONDRICH: That's the people right there,
25 honey. Go ahead. That's their faces. Go ahead.

1 MS. KONDRICH: Where they at?

2 MR. KONDRICH: Right here. These are them.

3 Okay?

4 MS. KONDRICH: Oh, there you are. Read this --

5 MR. KONDRICH: Yes.

6 MS. KONDRICH: -- to them?

7 MR. KONDRICH: Yes.

8 MS. KONDRICH: My name is Chloe Emmanuel

9 Kondrich. I was born on May 16, 2003, in Pennsylvania.

10 Not only was I born the most beautiful baby in the world,

11 but I was born with Down syndrome. Some people said I

12 would not be able to do much, and they were very wrong. I

13 love to read, dance, travel, and play golf, basketball,

14 volleyball, and baseball. I am 17 years old now and have

15 done so many fun, amazing things. I have met the President

16 and Vice President and my picture hung on the wall of the

17 White House. I have spoken at the United Nations twice. I

18 have been on the big screen in Times Square five times. I

19 even have a Pennsylvania law named after me. It is called

20 Chloe's law. I have spoken in many cities, and I have

21 received many awards from across the country. I love

22 helping kids like me because Jesus made us perfect.

23 Thank you for coming to hear my dad and I talk

24 today. Please support and pass the Down Syndrome

25 Protection Act because the world needs more people like me.

1 Embrace, don't erase, Down syndrome. God bless.

2 MR. KONDRICH: Okay. Thanks, Chloe. And I
3 apologize again for our audio problems, and I hope you can
4 hear me. I had to mute my phone to be able to talk.

5 I had a visual. I'm not sure if Whitney is able
6 to put that up there. If she's not, I can continue without
7 it. I don't have the ability to send her a visual so that
8 I can -- I'd like to show pictures when I'm talking about
9 my daughter and the experience we went through, so I'm just
10 going to talk through the things.

11 As Chloe indicated, she was born in 2003 with a
12 diagnosis of Down syndrome. My wife and I were 40 at the
13 time. And during the pregnancy, we were pressured many
14 times to have prenatal tests. At the time, I was actually
15 a sitting police officer in Pittsburgh, and I questioned
16 them. I said why are you pressuring us to have tests? And
17 they said it's because you're high risk, and the keyword
18 was risk to have a baby with Down syndrome. And I said to
19 the lady, who was the medical professional who was doing
20 this, I said what are our options if we have the test, the
21 prenatal test for Down syndrome? And she told me you can
22 make a decision. I say, well, what kind of decision? And
23 she said whether you want to keep your child or not. So
24 that was our first experience with that. We weren't given
25 any positive -- we refused the test, and in 2003, May --

1 actually, my daughter's birthday is coming up -- Chloe was
2 born.

3 After she was born, we learned from talking to
4 other parents that 70 to 90 percent of children diagnosed
5 prenatally with Down syndrome were identified, targeted,
6 and terminated. We also learned that in the country of
7 Iceland that 100 percent of babies -- there hasn't been a
8 baby born with Down syndrome in Iceland in the last seven
9 years. They've all been terminated, which I like to refer
10 to as a prenatal genocide.

11 And it kind of put things in perspective. You
12 know, if Chloe was an animal or a species in Iceland, she'd
13 be covered under the Endangered Species Act and it would
14 actually be a Federal crime to actually even hurt an egg of
15 a person or species like Chloe.

16 And in the United States of America in 1973 we
17 legalized abortion with *Roe v. Wade*, but we also passed the
18 Endangered Species Act the same year, which criminalized
19 killing endangered animals but legalized killing endangered
20 people like my daughter. If you destroy an egg, which is
21 an unborn eagle, then you can go to jail for a substantial
22 amount of time, receive a very huge fine, and, you know,
23 have your life basically ruined. And I'm a very big animal
24 protector. I love animals. But it's kind of ironic that
25 we protect animals and unborn animals -- that's what an egg

1 is -- while we legalized terminating people like my
2 daughter Chloe.

3 After Chloe was born, it was a negative stuff
4 from the medical profession, but we started focusing on her
5 abilities, not her disability, and we plugged into
6 Pennsylvania early intervention, which I want to salute all
7 of you Members of the Legislature, House and Senate,
8 because I know it's been a bipartisan support for
9 supporting that. I think we're the best early intervention
10 in the country and started focusing on her abilities. And
11 now Chloe is 17. She'll be 18 next month and, you know,
12 she is doing amazing things.

13 Thanks to early interventions, as Jessica alluded
14 to earlier, Chloe was reading at age 3 and now at age 17,
15 going on 18, she reads almost at grade level. She actually
16 reads better than a lot of the police officers I used to
17 work with. She reads billboards, she reads magazines, she
18 reads books. Nowadays, kids with their devices, she loves
19 her books.

20 Chloe went to preschool class at age 3. Once
21 again, I'm going to thank the supports and services in
22 Pennsylvania. And I'm going to go through these slides
23 real quick just, like I said, to give you a visual of what
24 she's been doing in her neighborhood schools, inclusive
25 classrooms. You know, we use the term typical, but anybody

1 out there knows that no child is typical. So Chloe has
2 been with typical peers going through. This is her
3 preschool class, kindergarten, first grade, second and
4 third grade, fourth, fifth, sixth, seventh, eighth and
5 ninth, 10th and 11th, get up there, and she's in 11th grade
6 now. And, as I said, she has many abilities.

7 Chloe's picture has been picked out of thousands
8 of pictures in October during Down Syndrome Awareness Month
9 and has been on the big screen in Times Square five times
10 up in New York City.

11 Chloe's best friend -- I like to bring this up
12 too, as we talk about the -- Chloe's best friend is her
13 brother, and her brother is the person he is today because
14 of Chloe. And I often think of all the people in society,
15 the siblings that missed out having a brother or sister
16 with Down syndrome. She's made him into the type of man
17 that our society needs more of who serves others and
18 protects others and has a heart for individuals, you know,
19 who need protecting.

20 Chloe has brought a lot of light to our
21 community. You know, as I said, I was a police officer in
22 the city. She helped bring comfort to the family of a
23 police officer in Pittsburgh that was killed in an ambush
24 and actually told them things about -- he was a good friend
25 of mine, Paul Sciullo, that he was doing up in heaven that

1 only the parents knew, and that's another story I could
2 tell you about on another day.

3 Chloe's on the cover of a book. It's called
4 *Brilliant Souls*, and it talks about the gift of Down
5 syndrome and what people -- and also references the 90
6 percent-plus termination rate for kids like this. She's
7 been in articles across the country. And I share this with
8 you because she's a Pennsylvania resident, and she's
9 someone that you as Pennsylvanians should be proud as a --
10 matter of fact, in a month she'll be a registered voter --
11 the accomplishments and the abilities that she has done to
12 advance and show what a great State we have.

13 She's been nominated for a regional Emmy award
14 for a TV show that she was in. She's visited the French
15 Consulate up in New York City.

16 And, you know, after her birth and watching her
17 abilities, I decided to leave my policing career and just
18 become an advocate and to advocate not just -- and I like
19 to make this statement very clear. I'm not just pro-birth.
20 I am pro-life. And to be a genuine pro-life person means
21 that you advocate for supports and services that allow a
22 child, once they get here, to have a good life from
23 conception to natural death. So that's what I devoted my
24 second phase of my life after Chloe's birth.

25 I actually was appointed to chair the Governor's

1 Advisory Council for Early Intervention under Governor
2 Rendell. I served under Governor Rendell, under Governor
3 Corbett, and also under the first term of Governor Wolf.
4 And, like I said, I look at these things, supports and
5 services as bipartisan. They're not Republican, they're
6 not Democrat, they're not political. If you don't support
7 these services, I've told legislators before, then you're
8 not pro-life. And they'll say, well, I don't believe in
9 abortion. I say, yes, you're pro-birth but you're not pro-
10 life.

11 So Chloe and I made it our mission to come to the
12 Pennsylvania Capitol. We've been up here many times.
13 We've spoken up here. I'm sure we've met with many of you
14 about how important these are, like I said, for having a
15 good life. And as we were doing this, you know, we kept
16 hearing these stories of people not being told the correct
17 information about Down syndrome, and I agree with what
18 David testified earlier. There is a law in Pennsylvania
19 which I'm going to talk about that mandates that
20 information but it's antiquated, so that would be a great
21 thing to form a bipartisan committee to update what
22 currently exists for what's called the Down syndrome
23 Prenatal Education Act. And that was Chloe's law. And
24 that was just something Chloe and I basically came up with
25 one day, wrote it on a legal pad, started doing advocacy up

1 there. So we do have legislation in Pennsylvania that
2 mandates that when a parent gets a prenatal diagnosis
3 they're given the factual support of uplifting information
4 that will help them to have a good life with this child.

5 And what was really cool about that law -- if you
6 could advance that next slide, Whitney -- it passed 50 to
7 nothing in Pennsylvania Senate, and it passed like 198 to 2
8 in the House, so it shows that Pennsylvania as a State and
9 our legislators from very diverse cities and backgrounds
10 are united in making sure that people who do get these
11 diagnoses do receive positive, uplifting information.

12 And, like I said, you know, we cannot be genuine
13 pro-life people -- you can go up a couple slides -- unless
14 we support the services that allow a person to have a good
15 life. Actually, Chloe signed the law at the Pennsylvania
16 Capitol.

17 So we continue -- when the law was passed, it did
18 get a major focus across the country. I think it helped to
19 fuel what they referred to as the pro-information movement,
20 which I'm a very big proponent of, of getting information
21 out. You know, information is only good if people know
22 about it, so Chloe and I just started talking across the
23 country, going around and, you know, promoting what our
24 kids are able to do. And Chloe's law actually was featured
25 on the second page of the *South Korean Times*, which is one

1 of her friends Alex Lee signed a law also, so that was
2 pretty neat to see that from a Pennsylvania perspective. I
3 can't tell you what that says, but I was told it was
4 something positive.

5 So what is the message from Chloe's law? The
6 message is -- you know, it was Pennsylvania proud that we
7 are pro-information, and we are a State that does embrace
8 children, individuals with not just disabilities but
9 different abilities. And the law allowed Chloe -- she
10 received a *Pittsburgh Business Times* Health Care Hero
11 award, and it has led us to opportunities that help us
12 promote what people with Down syndrome are able to do.

13 The next slide will show you Chloe and I have
14 spoken to the United Nations in New York City twice in
15 front of global audiences with a few translators and
16 everything. And these pictures, the one on the left, I
17 think it's appropriate for today. That's the ambassador
18 for Russia and the ambassador from Saudi Arabia, and Chloe
19 is signing books for them and talking to them, and she
20 actually flashed a peace sign down the middle. And I often
21 say, you know, these individuals are messengers who would
22 bring out a peaceful message to the world that's
23 desperately needed, as we all know, now more than ever.

24 Chloe has been on a radio show with Cardinal
25 Dolan up in New York City. And we can go through these

1 fast. She's received several awards of New York City and
2 around the country for her advocacy, and actually an
3 organization up in New York named an award after Chloe and
4 gave her the Chloe Award, which was presented to her.

5 She's met with Dr. Alveda King, who was Martin
6 Luther King's niece, and we've received an award from her
7 last year, and she is another one who highlights, you know,
8 how abortion with prenatal testing can be used for what's
9 happening right now, which is, I do, I call it a prenatal
10 genocide.

11 And as I'm wrapping things up quickly here, you
12 know, I like to ask people -- you know, Chloe has met with
13 the President and Vice President, President Trump, Vice
14 President Pence, and actually her picture hung on the West
15 Wing of the White House wall. I think that's the only time
16 that's ever happened until the current Administration just
17 recently took over. And so you can show that next slide,
18 the picture on the White House wall. And she was invited
19 to the White House Christmas party this past year.

20 When we spoke at the United Nations, there was a
21 reporter there from Italy. She did a global story about
22 her advocacy. It's gone out to several million people, in
23 I think 12 different languages, so it's another opportunity
24 to promote what people with Down syndrome, what their
25 abilities are.

1 And, you know, our mission right now as we're
2 testifying in support of the Down Syndrome Protection Act
3 is to serve and protect. You know, if we as a society
4 don't protect our most vulnerable -- and as Jessica
5 referenced, there is a waiting list to adopt kids with Down
6 syndrome. I would take 10 more to be honest with you.
7 She's my easier child to raise. And the information and
8 the stuff that's given out is not correct. That's why we
9 worked for that legislation. And, you know, I came to
10 testify today with the hope also we will update the
11 information that's given out under the Down Syndrome
12 Protection Act, Chloe's law.

13 And, you know, defending and protecting our kids
14 is our most important thing we have as a society, you know,
15 and Dietrich Bonhoeffer said, "Silence in the face of
16 evil is itself evil. Not to speak is to speak, and God
17 will not hold us guiltless." And, you know, originally if
18 you go back to the Holocaust, the first people that they
19 got rid of or were able to say were worthless were people
20 with disabilities. Those were the first people they got
21 rid of.

22 And I like to ask this question is, you know, as
23 prenatal testing advances, we see how fast it's advancing,
24 who's next? What if we get a prenatal test for autism?
25 How about for depression? How about for baldness? How

1 about for ADHD? You can get rid of me. How about for OCD?
2 How about for, you know, being short or for having brown
3 hair or whatever? It's the ultimate form of
4 discrimination, prejudice, profiling, bigotry, bias,
5 exclusion, and it's eugenics. And, like I said, when a
6 society says we can get rid of a person just because they
7 don't meet the cultural mandate for perfection, I think
8 we're all in trouble, and it's something we need to examine
9 internally.

10 And, like I said, this is not a political
11 question. It has nothing to do with politics or
12 Republican, Democrat. It has to do with just life and
13 respecting people for who they are. And should we
14 determine that if a person fails a test, then they should
15 be terminated with, you know, an innocent person, just to
16 think about that.

17 A final thought I have for you -- and this is
18 from my police perspective, you know, people with Down
19 syndrome, I will tell you this, they have no malice. They
20 can have behaviors, but they don't have malice. They would
21 never intentionally hurt anybody. I don't ever remember a
22 mass shooting with a person with Down syndrome or somebody
23 in a drug sting operation or all the horrific headlines we
24 read on a daily basis, so I'd like to ask you all when you
25 go watch the nightly news, who are the disabled people in

1 our culture, and who are the next to face a prenatal
2 genocide as testing advances?

3 So I thank you again. I just ask you to support
4 the Down Syndrome Protection Act, and I thank you for
5 allowing us to testify today. I wish we could be there in
6 person, but thank you. God bless you, and thanks for all
7 you do in Pennsylvania to support individuals like my
8 daughter Chloe. Thank you.

9 MAJORITY CHAIRWOMAN RAPP: Thank you, panel. I
10 truly appreciate your testimony. I'm honored to say that
11 I've met Kurt and Chloe on several occasions, and you've
12 really opened the eyes and heart and souls of many, many
13 people here at the Capitol. And to Jessica and David, I
14 appreciate all of your testimony, too.

15 And at this point in time -- as you know, we're
16 in the middle of the hearings. We did pass the Down
17 syndrome bill last session, and it will be before us
18 shortly here in the House, and this Committee will be
19 taking up this legislation. But I appreciate all of your
20 comments.

21 And at this point I'll see if Members have some
22 questions. Representative Benham.

23 REPRESENTATIVE BENHAM: Thank you, Chairwoman,
24 and thank you, Jessica, David, Kurt, and Chloe, for your
25 testimony today.

1 My name is Jessica Benham. I have autism. I'm
2 autistic. And as far as I know, I am the only openly
3 developmentally disabled Representative in Pennsylvania
4 State Legislature. So reproductive justice for people with
5 disabilities, particularly those with developmental and
6 intellectual disabilities, is very close to my heart, so
7 thank you all for your testimony today.

8 I heard each of you talk about the need for
9 supports and services for people with IDD. Jessica, you
10 spoke specifically about a need for an increase in funding
11 for those services. David, you talked about how parents
12 and pregnant people might be worried that they would not
13 have the resources to raise a child with Down syndrome.
14 And, Kurt, you talked about the need to advocate for
15 supports and services for people with Down syndrome to be
16 able to lead a good life. I'm wondering if each of you
17 could talk about what an increase in funding for State
18 supports and services would mean for people with Down
19 syndrome and their families a little bit more?

20 MS. CAPITANI: I personally would like to spend
21 more of the time today -- I mean, there are so many things
22 we could get into, but it seems like that would be a
23 different hearing than what we're talking about today. But
24 I would defer if David or Kurt wanted to add anything
25 specifically.

1 MR. PERRY: I mean, I can add -- am I on? Yes.
2 I would just like every lawmaker at every level of
3 government across this country to think about to what
4 extent they're asking people to center their skills and
5 their strengths or to center their suffering and their
6 struggle and then what message that sends. You know, I
7 think that from the issues of prenatal testing all the way
8 until the end of life in part because of medicalized
9 systems and how we have interpreted informed consent, we
10 end up just presenting list after list of risk factors and
11 problems.

12 And it was a challenge, you know, when the first
13 time I heard the words Down syndrome and the doctor started
14 listing risk factors, and, you know, just dozens of things
15 that might happen someday, none of which were happening
16 right then. And, you know, that was a hard couple hours
17 there at the beginning. So right now where I have to
18 document my son's struggles -- we have distance education
19 in order to try to fight for support during this pandemic.
20 When he's an adult -- I mean, it's just a constant
21 narrative of struggle as opposed to saying, you know, here
22 are the strengths, here are the ways in which the State can
23 do better.

24 And I'm happy advocate for more funding, and I
25 think a lot of people are doing that, and I'm grateful to

1 everyone who is looking to just raise the dollar amount,
2 that's great, but I also think we have to figure out how we
3 access that dollar amount.

4 And I always think, you know, here, you know, if
5 people -- I have a lot of advantages, and I suspect all of
6 us here testifying have a lot of advantages. We all seem
7 to be, you know, at least first language in English, you
8 know, we all are currently on the internet, right, so that
9 says something. You know, if we're having trouble
10 accessing these services and managing through these
11 enormous bureaucratic systems, you know, what is like for
12 people who don't have those advantages? Again, I'm happy
13 to think about more money, but I want to make sure that we
14 can get to what we have right now as well and that
15 everyone, no matter where they come from, can do that.

16 REPRESENTATIVE BENHAM: Well, thank you. I
17 really appreciate that. I think you're exactly right. We
18 need to think about not just the amount of money that's
19 there in our State system to support people but also about
20 how we force families and parents to focus on deficits
21 rather than on the whole person.

22 I think, for example, about -- Rep. Klunk has a
23 great bill around medical assistance for workers with
24 disabilities. I think there's a variety of things that we
25 can think about, whether it's more waiver funding, et

1 cetera. So thank you for that.

2 The second question that I have, Jessica, you
3 talked about how folks with Down syndrome are exceeding
4 expectations, including, you mentioned, many of them
5 getting married. And of course, you know, I know that
6 parents want what's best for their kids, right? I know my
7 parents -- I'm not a parent myself, but my parents want me
8 to find a partner in life, to potentially have kids myself.
9 And so with more people with Down syndrome getting married,
10 finding partners, I think about what reproductive justice
11 looks like for people with Down syndrome who might become
12 pregnant or have kids themselves.

13 And one of the things that I've noticed is that
14 even for folks with Down syndrome who have a Medicaid
15 waiver from the State, those waivers do not allow direct
16 support professionals to help with any tasks of parenting.
17 And so I'm wondering, as you think about your own children
18 and, you know, other people with Down syndrome and you
19 imagine their futures and what that might hold, including
20 parenting, how do we envision a world in which we support
21 folks with developmental and intellectual disabilities who
22 may very much want to have children and families
23 themselves?

24 MAJORITY CHAIRWOMAN RAPP: Jessica, I believe
25 you're muted. I see you trying to speak there.

1 MS. CAPITANI: Thank you. Thanks. Thank you,
2 Representative Benham. You're touching on, you know,
3 dreams that, yes, I definitely have for Caden. We haven't
4 hit the development of stages, so I'm trying to deny that
5 it's going to happen. I'm not ready yet. But, yes,
6 traditionally, funding for everything from special
7 education to direct support professionals that you
8 mentioned has been underfunded, State level, Federal level,
9 all the way around, so all of that could be buoyed up or
10 even, as David mentioned, not necessarily just more money
11 but just the ways that we access the money could be
12 certainly made a lot easier. There's so much red tape and
13 difficulty even just all the technology, the deadlines,
14 everything. And there is just folders and entire drawers
15 of them in my spare bedroom just to access everything for
16 Caden that he by law has a right to for services. So, yes,
17 all of that could be streamlined, made easier.

18 REPRESENTATIVE BENHAM: Thank you. David or Kurt
19 or Chloe, anything to add?

20 MR. KONDRICH: Can you hear me?

21 REPRESENTATIVE BENHAM: Yes, I can hear you.

22 MR. KONDRICH: Okay. Chloe, you know, like Chloe
23 is going to be 18 and, you know, she's an adult. She's
24 charting her own future. I've had people come up to me
25 with Chloe and say, oh, is she going to work at Giant

1 Eagle, you know, assuming the assumption that she's going
2 to bag groceries at Giant Eagle. And I respond, well,
3 actually, she -- no, she should be the manager managing
4 your daughter who's bagging groceries. But, I mean, I
5 think that's another stereotype we have to break. Yes,
6 she's in charge of her future. And, you know, she would
7 love to public speak. I can see her working in a preschool
8 with kids one day. She loves to do those kind of things.

9 So I think that's another thing we have to focus
10 on as well. What do they want to do? What's their plans
11 for the future? Not everybody does get married. Everybody
12 has this or that, and I just think, you know, as Jessica
13 and David both beautifully articulated, this is a great
14 time to have Down syndrome because, you know, it's better
15 than ever and, you know, it's really sad that with
16 technology and prenatal testing is now not allowing these
17 individuals to come into this world to show, you know, all
18 the things that they're capable of doing. You know, and
19 sometimes people assume just because you have Down syndrome
20 you want to be friends with somebody who has Down syndrome.
21 You know, they're all different. Chloe's likes, her
22 dislikes, her sports, her diet, it's all different, and I
23 just think it's a thing that we have to really keep in
24 perspective as a society.

25 REPRESENTATIVE BENHAM: I absolutely agree. I

1 mean, by my very presence in the Legislature I break
2 stereotypes and boundaries and stigma every day for what
3 people think that folks with developmental disabilities are
4 capable of, so maybe if she wants, Chloe will be a State
5 legislator someday. We'll see. I would love to have her
6 as a colleague and appreciate, you know, her testimony here
7 as well. It's nice to not be the only developmentally
8 disabled person in a virtual room.

9 I appreciate all three of you for talking today.
10 Like I said, this is an issue that's close to my heart, and
11 I would encourage all of my colleagues here today to
12 support legislation that dreams bigger about what people
13 with disabilities are capable of in our lives and support
14 legislation that does more to protect disabled people like
15 my crisis standards of care legislation and provides more
16 funding that focuses on what we're truly capable of in this
17 world. Thank you.

18 MAJORITY CHAIRWOMAN RAPP: Thank you,
19 Representative.

20 Our next question comes from Representative
21 Klunk, who is the sponsor of the Down syndrome bill.

22 REPRESENTATIVE KLUNK: Thank you, Madam Chair.
23 And thank you so much to our testifiers today. It's so
24 great to see you.

25 David, I have not met you before, but thank you

1 so much for joining us. And I know it's great to see
2 Jessica and Kurt and Chloe again on this issue.

3 It has been an honor and a privilege to be the
4 prime sponsor and supporter here in the House of
5 Representatives of the Down Syndrome Protection Act. And
6 the families and the individuals living with Down syndrome
7 throughout our Commonwealth have been the driving force
8 behind my advocacy for this particular piece of
9 legislation.

10 And as Representative Benham from Allegheny
11 County has pointed out, I am a proud supporter of the
12 Medical Assistance with Workers with Disabilities Act that
13 I have been working on with my good friend and Chairman
14 here in the Health Committee, Representative Dan Frankel,
15 which I think goes to show how much we do support our
16 individuals living with disabilities here in Pennsylvania
17 and how we can work together on these issues to provide
18 those additional supports that are very much needed that we
19 have heard from from you guys today about.

20 And I would encourage you -- I know, you know,
21 that this is a little bit of a -- the hearing isn't on, you
22 know, supports and access to care when it comes to
23 disabilities, but I would encourage all of you to
24 communicate to us not only about additional funding but
25 that access to care and how we can work together to provide

1 those abilities for your children and your families to
2 better access that care because at the end of the day where
3 government isn't working in that space we need to do
4 better, and we need to work together to solve those
5 problems to make sure that every Pennsylvanian, if you need
6 access to care, can get that.

7 I also wanted to talk about one thing that I know
8 David had brought up and Kurt and Chloe have been huge
9 advocates on is that pro-information movement when it comes
10 to that prenatal diagnosis of Down syndrome and some of
11 these other potential diagnoses. My question to you guys
12 is how can we do better in that space? You know, it was
13 2014 I was not here in the legislature at the time when
14 that bill was passed but certainly would have been one of
15 the supporters of it.

16 But as we move forward in this space I know just
17 probably in the past six to seven years a lot has changed
18 in this space. And where can we do better maybe with an
19 update on Chloe's law to make sure that parents who are in
20 that room, receiving that diagnosis, have all of the
21 information available to them so that they can make, you
22 know, that best decision for their family about how they
23 are going to handle that diagnosis and fully better
24 understand all of those services that might be available to
25 them and how can we make that better? Because I do believe

1 information is power and making a decision for your family.

2 So how can we do better with that?

3 MR. KONDRICH: Well, you have a parent panel here
4 right now who would love to help you. We have the
5 legislation, which is a blessing. We have it. It's there.
6 It's like anything. It'd be like having legislation
7 that's, you know, for a motor vehicle law for a type of car
8 that doesn't exist. So we do have it, but, you know, I
9 think, like I said, right here, we have a parent panel and
10 people are passing I'm sure -- maybe I'm speaking ahead for
11 David and Jessica. We would love to help you update that
12 and work with bipartisan legislators just to make sure that
13 that -- I love what David said. You know, I'm not
14 brilliant, but I have a degree and I can't muddle through
15 half this stuff. And I think of a family, maybe a single
16 parent or whatever trying to access these supports and
17 services, so I think, Representative -- and, once again,
18 thank you for the amazing work you do up there -- that
19 forming a parent panel, people that live it, and getting
20 our feedback.

21 You know, Jessica has an amazing book I think
22 should be going to all parents out there to see the
23 positive things about individuals with Down syndrome, and
24 we would love to help you since we live it, just update the
25 site and update the information that's being disseminated

1 out to parents because, like I said, we have the
2 legislation, so let's just do what we can to update it now
3 and make it so, you know, it's really accessible, it's out
4 there, and that people, you know, are able to easily get
5 through the system and see all the good things that are
6 available.

7 MR. PERRY: I just want to say -- sorry, Jessica,
8 do you want to go? Okay. I'll be quick.

9 I just want to say thank you to Kurt and Chloe
10 for the work they've done on passing this legislation. I
11 mean, that wave of bills that were passed really in the
12 earlier part of the last decade were just so important.
13 But, you know, there's a lot of work to do. I'm a big fan
14 of -- I'm sorry, I'm getting a little bit of feedback, but
15 hopefully you can hear me.

16 I am a big fan of Lettercase.org if people just
17 want to go look for what I think is a really vibrant model.
18 I mean, they have for a number of different diagnoses but
19 including Down syndrome. It's beautiful, it's colorful,
20 it's filled with individual stories. It has accurate
21 medical information, right, so it meets the standards for
22 informed medical consent, but it leads with humanity. It
23 leads with our shared humanity. And I don't work for
24 Lettercase. I have no stake in them. I just think that
25 they are a good model, and I'm sure there are others.

1 And, you know, I want to make sure that we lead
2 with humanity. And then many things will happen as a
3 result of that. And, you know, it's just such a vulnerable
4 moment, the first time you hear the words Down syndrome.
5 It is such -- I mean, I have a lot of -- I could feel it in
6 my heart right now, that moment, and you've got to -- you
7 know, I don't want to put the weight on the parents to go
8 on these websites. I want to put the weight on every
9 single person involved in talking to those parents at those
10 moments. I want them to understand the whole picture and
11 to lead with humanity and to be pushed to do it, to be
12 pushed by the force of the law to know this information and
13 convey it in a way that really meets that vulnerable person
14 where they're at and carries them to a better place where
15 they're not lost in misinformation and fear.

16 And again, I mean, I think that there are limited
17 opportunities to do this kind of meaningful bipartisan
18 work. We're in a polarized, difficult time in this
19 country, but this is one. This is a place we can really do
20 it. So I would like to see a lot more energy put into that
21 than into things that divide us.

22 MS. CAPITANI: And I would just add that it's not
23 a once-and-done. You don't just put out the information
24 about Down syndrome and there it is, that it does need to
25 be revisited. Things are changing and developing, and so

1 the book that Kurt mentioned that I was involved with
2 *Gifts: Mothers Reflect on How Children with Down Syndrome*
3 *Enrich Their Lives*, when that was put out even 10 years
4 later the group of mothers that were involved in writing
5 that said we need to update our book, and so we rereleased
6 it. And that's with parents just updating their
7 information, so certainly medical information, educational,
8 all of that needs to be revisited on a regular basis.

9 And also talking to other mothers who did receive
10 a prenatal diagnosis definitively like myself, there is
11 such a huge breadth of that experience, some being told
12 outright that they should abort several times by different
13 specialists that they might've seen, some receive a
14 referral to a genetics counselor, some do not. I mean,
15 it's very unfair that it isn't a more controlled
16 environment on the information that everybody doesn't have
17 access to the same valid information about Down syndrome.

18 And I think that, as David and Kurt both said,
19 this is a great bipartisan issue that we can all agree on,
20 and it's a great first step in my opinion to validating the
21 rights of people with Down syndrome.

22 REPRESENTATIVE KLUNK: Thank you. And, Madam
23 Chair, if I may do one quick follow-up on that with
24 Jessica.

25 MAJORITY CHAIRWOMAN RAPP: Yes, Representative,

1 go ahead.

2 REPRESENTATIVE KLUNK: Since, Jessica, you know,
3 you are the mom in the room and you said that, you know,
4 you had that experience -- and this was prior to Chloe's
5 law, correct, when you gave birth to Caden, so you wouldn't
6 have experienced that access to the information, correct?
7 So my question to you is now that you've had your
8 experience with Caden, you know, you know, what's available
9 out there under Chloe's law, but still, how can doctors and
10 healthcare practitioners in that space when they are
11 talking with that mother in that moment of testing, how can
12 they do better, and how could we potentially help them do
13 better?

14 I, you know, myself have gone through two
15 pregnancies. I have done the prenatal testing, and I will
16 tell you with my first pregnancy when I selected to do that
17 prenatal testing, there was that subtle -- there's just a
18 subtlest to that conversation that I had had with that
19 practitioner that just led me to believe that it was a
20 little bit of a steering towards we can take care of that
21 if that comes up. And that still sits with me to this day
22 as a pro-life advocate and legislator. And that
23 experience, again, still sticks with me. So, Jessica,
24 again, as a mother, as a woman who went through that, how
25 can we do better? How can the healthcare industry do

1 better in providing that service to moms at that moment?

2 MS. CAPITANI: I do feel that the medical system
3 feels obligated to warn you of every possible complication,
4 every medical condition that might be related. And it's
5 definitely skewed to this very clinical tone. And the
6 doctor that spoke with me, you know, he's not a social
7 worker, he's not a trained counselor. He doesn't know
8 about special education. He couldn't answer some of the
9 basic questions. And it was very unfair to me. I needed
10 more than just all the clinical information.

11 It was also, I think that, you know, as I
12 mentioned about the study that there is systemic ableism
13 built into the medical system. So it, like I said, shifted
14 my whole pregnancy. From the moment I got that diagnosis I
15 was treated differently because of that and handled
16 differently. I felt like everybody was walking on
17 eggshells around me.

18 But I think that they need to remember that if I
19 have that baby before the diagnosis, I still have that baby
20 now, and I want him to be spoken about in a certain way and
21 to certainly focus on taking my lead. If he's doing his
22 job well, the doctor should know me better, and if he
23 doesn't refer me to somebody else who can help me make
24 those decisions, I ended up on my own having to search out
25 information on cardiology, neurology. I spoke to a

1 pediatrician, I got a second opinion on what was being
2 shown in the ultrasounds because I was not given that
3 information initially. I didn't receive information about
4 the waiting list. I would have loved to have been hooked
5 up with a family who was actually traveling this path so I
6 could envision it. And none of that is involved in this
7 very clinical setting.

8 REPRESENTATIVE KLUNK: Thank you so much for
9 that. And I think, you know, in this whole space there is
10 so much more than we can do to help moms and dads when
11 you're faced with that diagnosis in that, you know, medical
12 office but then also the follow-through throughout the
13 entire life of Chloe and Nico and your son, Jessica.

14 So thank you so much for being here today and
15 enlightening us and again showing us that the lives of your
16 children and your families are, you know, just lives that
17 we should be living here in Pennsylvania, so thank you so
18 much. It was so great to see you.

19 MS. CAPITANI: Thank you.

20 MAJORITY CHAIRWOMAN RAPP: Thank you,
21 Representative.

22 Do we have anybody -- do you have any questions?
23 Any questions?

24 I want to thank you very much for being with us
25 and sharing your stories. I just wanted to share to the

1 Members and to you and the public that we also received
2 through mail a testimony from the Shaw family, and it's
3 from Dr. Justin Shaw. And he expressed by letter many of
4 the same things that your three families, you know, have
5 gone through as a physician, and so his story is very
6 interesting. But he did provide this to us as written
7 testimony. So I thought it was very nice of him as a
8 doctor himself to share his story. So it's a very
9 interesting read. I encourage the Members to read his
10 written testimony.

11 And I want to thank you for being with us today.
12 I truly appreciate it. Chloe, it's always wonderful to see
13 you. I hope that you can -- the Capitol's open now. You
14 can come back and see all of us. And, Jessica, David, that
15 invitation is open to you as well to bring your children
16 into the Capitol. We would love to have all of you here
17 and see our beautiful Capitol of Pennsylvania. So thank
18 you again for taking time out of your busy schedule to be
19 with us, and we really appreciate your testimony, and thank
20 you for it. And have a great rest of the day.

21 MR. KONDRICH: Thank you.

22 MR. PERRY: Thank you all.

23 MS. KONDRICH: Thank you.

24 MS. CAPITANI: Thank you.

25 MAJORITY CHAIRWOMAN RAPP: Our next testifier is

1 Karen Gaffney, who is coming to us from Portland, Oregon.
2 So, Karen, I truly thank you for -- I'm sure you were up
3 very early to be able to be with us today virtually. I
4 heard you speak when you were here at the Capitol before --

5 MS. GAFFNEY: Yes.

6 MAJORITY CHAIRWOMAN RAPP: -- and I'm very much
7 looking forward to your testimony and your story. And you
8 may proceed.

9 MS. GAFFNEY: Okay. Good morning, everyone. I
10 am Karen Gaffney. Thank you for taking your time this
11 morning to listen to me and to consider what I have to say
12 on this matter. But, more importantly, I would like to
13 thank you all for working together to save the life of the
14 unborn child who may be born with Down syndrome or other
15 disabilities.

16 I work for a law firm about 25 hours a week here
17 in Portland, Oregon, where I live, and I also spend time
18 working on my nonprofit organization called the Karen
19 Gaffney Foundation. We are dedicated to championing
20 diversity to full inclusion in families, schools, the
21 workplace, and the community with people like me and other
22 disabilities. I earn the money from my nonprofit by giving
23 talks and workshops all over the country and sometimes out
24 of the country where I help people see that Down syndrome
25 is a life meant to be lived. This is a view not widely

1 shared by the prenatal testing industry, but you already
2 know that.

3 Most people in the Down syndrome community know
4 me because of my long-distance open-water swims. You see,
5 I've been a swimmer for as long as I can remember.
6 Actually, I could swim before I could walk, and I got into
7 open-water swimming after high school. Yes, that's right,
8 I graduated from St. Mary's Academy here in Portland,
9 Oregon, with a regular high school degree, and I was able
10 to go on to Portland Community College and earn a regular
11 associate's of science degree and a teacher's aide
12 certificate.

13 That was the year I swam a relay across the
14 English Channel. I have so many other open-water swims
15 like nine miles nonstop straight across the width of Lake
16 Tahoe, eight and a half miles across Lake Champlain, a six-
17 mile swim down the Columbia River to raise over \$80,000 for
18 the aquatic therapy program at Providence Health Systems
19 here in Portland, a five-mile swim from Molokini to Wailea
20 Beach in Maui to raise funds for Best Buddies of Hawaii.
21 Oh, and I also like to tell people that I am the first
22 person with Down syndrome to escape from Alcatraz. Yes,
23 that's right, I did say Alcatraz. I have done that swim
24 from Alcatraz Island where the prison used to be all the
25 way across the San Francisco Bay 16 times now, and unlike

1 some famous prisoners who have attempted that swim, I have
2 lived to tell about it.

3 These are just a few of my open-water swims, and
4 most of these swims are fundraising swims and swims to
5 raise awareness about what people like me with Down
6 syndrome can do. But, more importantly, I try to use my
7 time to help erase all that old data that is out there
8 about what we with Down syndrome cannot do.

9 There are so many young people with Down syndrome
10 who are growing up with the benefit of inclusive education,
11 speech therapy, physical therapy, medical intervention to
12 fix our bad hearts, our faulty hips, and our bad hearing.
13 There are phenomenal organizations providing medical
14 research to improve our life, not prevent them in the first
15 place. These organizations are racing to outrun the
16 prenatal testing industry, ladies and gentlemen, and your
17 bill will help us do that.

18 The progress we have made in the last 60 years is
19 so incredible. Do you know about Collette Divitto? She
20 lives in Boston, and when she got out of school, she kept
21 getting turned down for jobs probably because she has Down
22 syndrome. So she took matters into her own hands and
23 started her own company called Colletley's Cookies. Just
24 take a minute and look at what she has accomplished and
25 what she is giving back to her community.

1 How about John's Crazy Socks? John Cronin and
2 his dad started this great sock company, a great place to
3 go for that one-of-a-kind gift by the way. Not only do
4 they employ and train others with intellectual
5 disabilities, but they donate a percentage of their
6 proceeds to Special Olympics, to the National Down Syndrome
7 Society, and to other support organizations. And yes, John
8 has Down syndrome.

9 How about Chris Nikic? If you haven't read about
10 the first person with Down syndrome to complete an Ironman
11 triathlon, I hope you'll spend time this week as you're
12 working on this bill and read about this man and his plan
13 to get 1 percent better every day. He used that plan to
14 get ready for the Florida Ironman triathlon, which he
15 completed in November 2020. He wants you to take his
16 challenge to get 1 percent better every day. Set your
17 goal, make your plan, and help one other person with
18 disabilities to do the same. His success has inspired so
19 many people in the last six months, and he keeps paying it
20 forward. He is constantly bringing stuff out there to
21 raise funds for other organizations like Special Olympics
22 and Down syndrome support groups in Florida. And he has
23 the Hawaii Ironman in the fall to do it all over again. As
24 Chris likes to say, not everyone with Down syndrome will
25 complete an Ironman triathlon, but everyone can.

1 There are so many stories like these. If you
2 want more, I can send you hundreds more, but I would ask
3 that you each take some time and read about these three and
4 you'll be amazed.

5 We passed laws that ended our lives spent in
6 institutions for people like me. We passed laws that
7 opened up the classroom doors for people like me. We
8 improved our healthcare, and look at the results. We have
9 made so much progress in the last 60 years. It makes no
10 sense to ignore that progress and allow the prenatal
11 testing industry to end our lives before we can even take
12 our first breath.

13 Down syndrome is a life meant to be lived.
14 People with Down syndrome are living, growing, contributing
15 members of our communities, and we have a right to a place
16 in this world along with everyone else. And we belong
17 here. Thank you for listening to me this morning.

18 MAJORITY CHAIRWOMAN RAPP: Thank you, Karen.
19 Your testimony is so impressive, and we're very grateful
20 that you joined us today and shared with us your
21 accomplishments and those of many, many others across the
22 Nation and the world. I can say that I have seven
23 grandsons, and I have a couple grandsons that are just
24 totally into Crazy Socks and one that just insists on
25 wearing different socks whether they're Crazy Socks or not,

1 which is okay. But very truly, your accomplishments are
2 just outstanding and certainly go above and beyond. You
3 know, I think almost everyone has some type of disability,
4 but what you have achieved is really amazing. And I
5 certainly appreciate you taking your time, and hopefully,
6 we have some other questions.

7 I know that you touched on the fetal testing and
8 research, and that's certainly a huge threat to many women
9 when they get the news, as our parents just testified. And
10 where do you see the fetal research and the other testing
11 that you referred to -- what are you doing as someone with
12 Down syndrome to -- yourself trying to combat what happens
13 when a parent does receive that news as a successful person
14 with Down syndrome?

15 MS. GAFFNEY: Well, if a parent does receive that
16 news, you know, must be encouraged to try to do the very
17 best they can and to take it one step at a time. You know,
18 I try to help people see that we are on a journey of hope,
19 and I want parents to really encourage their child to, like
20 I say, do the very best they can and really have hope for
21 their child with disabilities.

22 MAJORITY CHAIRWOMAN RAPP: Thank you.
23 Representative Klunk has a question for you.

24 REPRESENTATIVE KLUNK: Sure, thank you, Madam
25 Chair. And thank you, Karen, so much for joining us today.

1 You truly are an inspiration to us all. I am not the best
2 swimmer, and I think I pretty much failed out of every
3 swimming course I ever took. But it's just so amazing to
4 see, you know, an individual like you out there just living
5 the best life possible and also advocating for those others
6 with disabilities and trying to make the world a more
7 inclusive space.

8 And I, again, just, you know, the bill that we've
9 been working on with Chairman Frankel in that space for
10 those individuals like yourself who have that, you know,
11 potential to really excel in the workspace, you know, with
12 an entrepreneurial, you know, spirit like you have with
13 your nonprofit and making sure that those individuals have
14 those opportunities despite having, you know, disabilities
15 to make sure that we can provide those medical services
16 when they need them I think is critically important.

17 And I think ultimately when individuals and
18 families know that those services are available and that,
19 you know, their children, when they get to be adults, will
20 have that ability to, you know, continue on and take that
21 new job or start a nonprofit or start a business, I think
22 that's going to be so important, you know, for them to make
23 that decision to embrace these children.

24 So what else can you offer us as policymakers?
25 You know, you have this foundation, you do this advocacy in

1 this space. What else can we do in addition to, you know,
2 the Down Syndrome Protection Act and some of the, you know,
3 other pieces of legislation like Chloe's law? But what
4 else can we do? Is there anything else that we can do as
5 legislators on this topic in this, you know, potential
6 disabilities space to make sure that we're, you know, doing
7 everything we can to support individuals, to advocate for
8 them, and provide the services that they might need to live
9 their lives and live those lives that are worth living?

10 MS. GAFFNEY: You know, I would say, you know,
11 try to do the very best we can and really tell the world
12 that we belong here, that we have a place in this world,
13 and we want to be treated the same way as anyone else.

14 REPRESENTATIVE KLUNK: At the end of the day
15 that's what we need to do. Thank you so much, Karen,
16 appreciate it. It's always good to see you.

17 MS. GAFFNEY: Thanks a lot.

18 MAJORITY CHAIRWOMAN RAPP: Thank you,
19 Representative and Karen.

20 Representative Twardzik?

21 REPRESENTATIVE TWARDZIK: Yes. Hi, Karen. I
22 just wanted to say it was great to meet you today. We've
23 been involved in sports for a long time doing a lot of
24 sponsorships with Ironman, and I'm surprised that you've
25 done 16 escapes from Alcatraz. And what have you done to

1 end up in jail 16 times?

2 MS. GAFFNEY: Well, I know that other people
3 haven't escape from the island, but I haven't. You know, I
4 just jumped off a ferry and swam all the way to the Palace
5 of Fine Arts.

6 REPRESENTATIVE TWARDZIK: Yes, that's just
7 fantastic, and I've been there for that race and it's just
8 amazing to see people do it. And, you know,
9 congratulations on your distant swimming, and you have
10 inspired me to get 1 percent better today. Thanks.

11 MS. GAFFNEY: Well, good, thanks. Have you heard
12 about Chris Nikic before?

13 REPRESENTATIVE TWARDZIK: Yes, we were involved
14 with Ironman for many years, and that's a great story also.
15 I've met Dickie Hoyt and Rick Hoyt, who have done Ironman.
16 John Maclean was one of the first people to do the Ironman
17 in a wheelchair, and it's just, you know, incredible
18 people, great people, and I'm glad to meet you, and I
19 really am inspired. I'm going to get out and exercise
20 today. Thanks.

21 MS. GAFFNEY: Good, thanks.

22 MAJORITY CHAIRWOMAN RAPP: Well, Karen, I thank
23 you very much. We truly appreciate you. You're an amazing
24 person, and certainly your accomplishments go beyond, you
25 know, most people. And I just appreciate you taking the

1 time out of your schedule. And I don't know what time you
2 had to get up this morning being out there in Oregon, but
3 hopefully you'll get back to Pennsylvania sometime. We'd
4 love to see you again. Thank you for sharing. Thank you
5 very much.

6 MS. GAFFNEY: Thanks. Thanks a lot.

7 MAJORITY CHAIRWOMAN RAPP: Our next presenter --
8 and, Members, we are running a little early today, which is
9 amazing. Our next presenter is Michele Clemens, who is a
10 licensed Genetic Counselor at Magee Women's Hospital. And
11 at this time, Michele, if you would mind if you could raise
12 your right hand, please, we have a rule in the House now
13 that we swear testifiers in.

14

15 (Witness sworn.)

16

17 MAJORITY CHAIRWOMAN RAPP: Thank you. And you
18 may proceed with your testimony. And thank you for being
19 here with us today.

20 MS. CLEMENS: You're very welcome. Thank you for
21 asking me to participate.

22 Just to repeat, I am Michele Clemens. I am a
23 Genetic Counselor in the Center for Medical Genetics and
24 Genomics at Magee Women's Hospital, which is part of the
25 University of Pittsburgh Medical Center. I have a

1 bachelor's degree in biology and a master's degree in human
2 genetics. I am certified by the American Board of Genetic
3 Counseling and hold a genetic counseling license in the
4 State of Pennsylvania and have been a practicing Genetic
5 Counselor for many years. I have practiced in the prenatal
6 realm and in the pediatric realm, so I have worked with
7 families who have a prenatal diagnosis of Down syndrome but
8 also families where the diagnosis was made postnatally.

9 Many years ago, the American Society of Human
10 Genetics defined genetic counseling and more recently the
11 National Society of Genetic Counselors reaffirmed that
12 definition, which is that genetic counseling is a
13 communication process. It is one where we are conveying
14 information in terms of interpreting and assessing medical
15 histories and family histories, looking at what is the
16 chance of a genetic disease occurring in a family. Our
17 role is to educate about the natural history of a
18 condition, the mode of inheritance, various types of
19 testing that might be available, management, prevention,
20 support resources, and research. We discuss various issues
21 related to making informed choices regarding that risk
22 assessment, family goals, ethical, religious beliefs and
23 values, and to encourage, support, and advocate for the
24 family.

25 One of the underlying mantras about genetic

1 counseling is that what we do is nondirective. Therefore,
2 we do not make decisions for our families. We don't make
3 recommendations either. We certainly recognize the
4 importance of accurate and detailed information and also
5 recognizing the difference between screening tests, which
6 may make a suggestion of a genetic condition, and
7 diagnostic tests, which actually provide a confirmed
8 diagnosis.

9 In our particular genetic center, we are actually
10 very fortunate to be able to involve the Down Syndrome
11 Center at Children's Hospital of Pittsburgh to all of our
12 patients who have a prenatal diagnosis of Down syndrome.
13 Although they've had some coordinator changes over the
14 years, the physician director and their coordinators have
15 been a valuable resource to our families who receive a
16 prenatal diagnosis.

17 But, as part of the genetic counseling process,
18 making patients aware of the option of pregnancy
19 termination is as well one of our responsibilities.

20 MAJORITY CHAIRWOMAN RAPP: Was that the
21 conclusion of your testimony?

22 MS. CLEMENS: I think so, yes.

23 MAJORITY CHAIRWOMAN RAPP: Okay.

24 MS. CLEMENS: Thanks. Representative Frankel I
25 think would like to make some comments.

1 DEMOCRATIC CHAIRMAN FRANKEL: Well, thank you,
2 Ms. Clemens. I appreciate you being here today. Also
3 having Magee Women's Hospital in western Pennsylvania is an
4 extraordinary resource, one of the best hospital facilities
5 to care for women in our State and also in my district, so
6 I'm pleased to have been supportive over the years.

7 I don't know if you heard the testimony of the
8 parents who were on earlier.

9 MS. CLEMENS: I did. I was listening.

10 DEMOCRATIC CHAIRMAN FRANKEL: And it was quite
11 compelling. And one of the things that came through
12 consistently through their comments was their feelings of
13 being afraid and unsupported, and particularly, you know,
14 once getting a diagnosis with a doctor. How can we expand
15 access to quality counseling in these situations?

16 MS. CLEMENS: Well, I think this raises one of
17 the issues that I think I have encountered over the years
18 is that the delivery of the diagnosis of Down syndrome may
19 occur by a variety of providers, and certainly I can speak
20 and I'm aware of how the process works when that diagnosis
21 comes through a genetic center. There is also a prenatal
22 genetic counseling program at West Penn Hospital, part of
23 Allegheny Health Network.

24 What we can't control is what happens when the
25 diagnosis is provided by just a physician in the community.

1 We have certainly tried to make -- I'm sorry, am I echoing?

2 DEMOCRATIC CHAIRMAN FRANKEL: We hear you fine.

3 MS. CLEMENS: Oh, okay. We certainly try to make
4 as many providers as possible aware of our services, and we
5 work with them to a great extent, but education becomes
6 then important. I'm not really certain how many providers
7 currently may actually be delivering that diagnosis outside
8 of a genetic center. That would really -- if you think
9 about the number -- well, let me back up and say we
10 consider a definitive diagnosis one that is going to be
11 based on the pregnant woman having a prenatal procedure,
12 amniocentesis or chorionic villus sampling from which
13 chromosome analysis is performed and in turn we get a
14 chromosome result confirming the diagnosis.

15 There are many screening tests which are offered
16 and available to pregnant women, and a screened positive
17 result from those is not a definitive diagnosis. And it's
18 very important for patients to understand that. Those
19 screening tests may be offered by the random provider, and
20 I have -- you know, how that result then is conveyed can
21 vary significantly.

22 DEMOCRATIC CHAIRMAN FRANKEL: Well, thank you.
23 And how would criminalizing the decision based on
24 information that you would provide affect your ability to
25 provide care?

1 MS. CLEMENS: I mean, we're still going to
2 provide the care that we provide. We are going to use as
3 many of the resources as we have to support our families.
4 As I said, the meeting with the coordinator of the Down
5 Syndrome Center is routine for us, and we want to continue
6 -- a prenatal diagnosis of Down syndrome may also involve
7 meeting with other pediatric specialties who may be called
8 in to care for a child with Down syndrome because of a
9 particular health problem or foreseen medical problem.
10 Providing the parents prenatally with those contacts, that
11 information helps them to appropriately plan and make
12 decisions.

13 It still comes down to being a personal choice
14 for any woman or couple that involves many, many aspects of
15 the diagnosis and the personal feelings for that patient.

16 DEMOCRATIC CHAIRMAN FRANKEL: Thank you very
17 much.

18 MAJORITY CHAIRWOMAN RAPP: Representative Klunk.

19 REPRESENTATIVE KLUNK: Thank you, Madam Chair.
20 And thank you so much, Michele, for joining us today.

21 I wanted to talk to you since you are a genetic
22 counselor and in this space, you know, technology and, you
23 know, understanding of our genes and where we come from and
24 all of that has just evolved so much over the past couple
25 of years. I actually just gave birth to our second child.

1 Our oldest is three years old. And even in that time
2 frame, you know, what has happened is absolutely amazing
3 from going in and talking to the doctors about what
4 different tests were available and how much sooner they can
5 find out if you're having a boy or girl, just technology
6 has advanced so much.

7 So I would love to hear from you, you know, where
8 are we in this space when it comes to prenatal testing?
9 When, you know, a woman comes in, what is the, you know,
10 soup to nuts, example of what can we test for now and when
11 can we test for this and what type of information are women
12 able to obtain about their unborn child through genetic
13 testing?

14 MS. CLEMENS: What we can learn is really very
15 vast. I mean, it's not the ability -- to give you a list
16 of conditions would be extremely long. But what we do is
17 -- sort of a general approach is we have some basic
18 perspectives that we look at. How old is the woman? This
19 goes back to recognizing that the chance of having a baby
20 with an extra chromosome condition, which includes Down
21 syndrome, increases with maternal age. But one thing that
22 we always tell our patients is that at no age is the risk
23 to have a child with a chromosome abnormality greater than
24 the risk to have a normal, healthy baby. And it's
25 important to put that into perspective.

1 We look at ethnic background because we recognize
2 that certain ethnic or racial groups have an increased risk
3 for a particular genetic disorder, sickle-cell anemia in
4 African Americans, certain individuals of Eastern European
5 Jewish ancestry have an increased risk for certain genetic
6 disorders. We look at family history. Has there been a
7 previous child or is there someone in the family with some
8 type of genetic condition which may, based on the mode of
9 inheritance of that disorder, increase the risk for that
10 particular patient? Are there other factors? Are there
11 maternal issues such as women who have diabetes and in
12 particular if their diabetes is not well-controlled have an
13 increased risk to have a baby with birth defects. So
14 looking at those various aspects, then often different
15 types of genetic screening or genetic testing will be
16 offered.

17 What probably has not changed over the years is
18 amniocentesis and chorionic villus sampling are available
19 for definitive prenatal diagnosis. Just for kind of basic
20 explanation, amniocentesis involves removing a sample of
21 amniotic fluid, typically performed sometime after 16 weeks
22 of pregnancy. Chorionic villus sampling is a biopsy of the
23 early forming placenta. It is targeting obtaining what are
24 called chorionic villi but the basic premise being that the
25 cells in the placenta and the genetic information in those

1 cells reflects that of the fetus. It's kind of very short
2 and quick version.

3 What testing we can perform on amniotic fluid or
4 chorionic villi sampling has vastly expanded over the
5 years. As we have learned more and more about particular
6 genes being responsible for a disorder, we may be able to
7 offer testing for that disorder for a family, particularly
8 if there may be findings on ultrasound that makes a
9 suggestion or because of a history of a previous child with
10 some type of problem, we may have that genetic testing
11 information to help guide us.

12 The other aspect that we look at are just
13 screening tests to try and determine is the particular
14 pregnant patient in some way at a greater risk for some
15 type of genetic condition? The American College of
16 Obstetricians and Gynecologists has a policy statement
17 which says that patients should be offered screening for
18 cystic fibrosis and a neuromuscular disorder called spinal
19 muscular atrophy. These are two more common genetic
20 disorders. They can occur in any ethnic or racial group.
21 And the incidence of them just makes them slightly more
22 common.

23 The bottom line here, though, is that the word
24 offered, it's not required, just that patients may be aware
25 of screening. These two particular conditions happen to be

1 inherited in such a way that both parents need to carry one
2 copy of a changed or a nonworking gene. And if the child
3 inherits a double dose or a copy from each parent, then the
4 child is going to be affected.

5 Now, just to make reference to commonality, about
6 1 in 25 to 1 in 29 individuals of northern European
7 Caucasian ancestry is a carrier for cystic fibrosis. That
8 carrier frequency does vary among various ethnicities,
9 however.

10 For many, many years there have been different
11 approaches to screening for Down syndrome and some extra
12 chromosome conditions. We, many years ago, started out
13 with something called alpha fetal protein screening. To
14 alpha fetal protein screening we added some other
15 substances produced by the pregnancy, and so now we have
16 something called quad screening or a multiple marker
17 screening with the idea being that pregnancies with certain
18 types of chromosome abnormalities there will be a general
19 pattern in the way the levels of these markers fall. And
20 what we receive from that testing is the idea -- we
21 generate a risk that the pregnancy is going to have one of
22 these conditions. Again, operative word is it generates a
23 risk. It doesn't give a yes or no definitive answer.

24 From that quad screening, then what developed was
25 a test called first trimester screening, a little bit

1 different. It is performed between 11 and 14 weeks. It
2 involves an ultrasound which measures a pocket of fluid at
3 the back of the baby's neck, something that is called
4 nuchal translucency. All developing embryos are going to
5 have some degree of nuchal translucency. But when it is
6 increased, that may be a marker for an increased risk for
7 some type of chromosome problem or birth defect.

8 In addition to obtaining that ultrasound, there
9 is a blood sample obtained, again, looking at a couple of
10 markers. All of the information is put together and,
11 again, a risk is generated, a chance that the pregnancy is
12 going to have one of these conditions.

13 More recently there is -- and let me just back up
14 and say from the perspective of Down syndrome, first
15 trimester screening is said to identify about 85 percent,
16 the second trimester screening identifying about 70 to 75
17 percent.

18 But more recently we have something which is
19 called noninvasive prenatal testing or cell-free fetal DNA.
20 This involves a blood sample from the mom which does a type
21 of counting comparison looking at the amount of material
22 from chromosomes 13, 18, and 21. It also does look at the
23 sex chromosomes. This testing is said to identify about 99
24 percent of Down syndrome.

25 Noninvasive testing, some labs will report the

1 ability to perform the test as early as nine weeks, but
2 certainly I think many centers have identified it's
3 probably best if it's performed at 11 weeks or after. But
4 these last three tests specifically are still considered
5 screening tests even though they have reasonable detection
6 rates. And so at least from our perspective as a genetic
7 center and in working with other genetic centers and labs
8 around the country, it is not considered a definitive
9 diagnosis. What will happen is that a diagnostic procedure
10 such as amniocentesis or chorionic villus sampling may be
11 offered to the patient to confirm the diagnosis. And I can
12 tell you in my experience, although rare, we have had
13 occasional false-positive and false-negative results.

14 REPRESENTATIVE KLUNK: Thank you so much for
15 that, Michele. Just a quick question for you. So those
16 screening tests oftentimes happen between 9 and 11 weeks
17 and then they would be followed up if there would be a
18 potential risk factor that would come out of those for a
19 potential Down syndrome diagnosis you would move onto the
20 diagnostic stage, the amniocentesis or the CVS would be
21 done. When would be amniocentesis or CVS be done in that
22 week spectrum?

23 MS. CLEMENS: CVS is performed between 11 and 14
24 weeks. Amniocentesis, pretty much after 16 weeks. We do
25 have patients who decline those procedures, and then our

1 perspective is to use detailed ultrasounds generally around
2 20 weeks. And because of the association of congenital
3 heart defects with Down syndrome, we quote that about 40
4 percent of fetuses with Down syndrome will have a
5 congenital heart defect. We routinely perform those two
6 imaging studies on all of our patients with that prenatal
7 diagnosis. And then in terms of following those patients
8 who continue pregnancies, they're followed more closely
9 with ultrasound than an unaffected pregnancy would be
10 followed. If there is a heart defect identified, often
11 there may be the need for a follow-up echo. The care
12 really becomes customized to some degree depending on the
13 patient, taking into consideration geographic
14 considerations and just what we are seeing with ultrasound.

15 A multidisciplinary subset from genetics here at
16 Magee Women's Hospital is something called the Center for
17 Advanced Fetal Diagnostics. I am one of the coordinators
18 of that center. And so this is a multidisciplinary team of
19 genetics, maternal-fetal medicine, ultrasound, pediatric,
20 specifically neonatology, and various other medical
21 specialties from Children's Hospital that follow patients
22 whose fetuses have been identified with some type of
23 problem. And that can vary from something quite mild, for
24 example, a clubfoot to a fetus that has multiple systems
25 involved.

1 REPRESENTATIVE KLUNK: Michele, thank you so
2 much. And it sounds like, you know, the women out at
3 Magee's Hospital have such a breadth of, you know,
4 assistance available to them with this type of a diagnosis.
5 It's great that you guys partner with the Children's
6 Hospital there to really wrap your arms around those
7 parents that received this diagnosis to make sure that they
8 are well taken care of, well-informed when they receive
9 that diagnosis. So thank you so much for the information.
10 I really appreciate it. And thank you for the work that
11 you do.

12 MS. CLEMENS: Thank you. And I will also say my
13 colleagues at West Penn Hospital provide the same type of
14 service. So I think western Pennsylvania has a very nice
15 network of services and provides great care for the
16 patients.

17 MAJORITY CHAIRWOMAN RAPP: Thank you.
18 Representative Benham, do you have a question?

19 REPRESENTATIVE BENHAM: Thank you so much,
20 Chairwoman, and thank you for your testimony today.

21 We've heard quite a lot of testimony today about
22 the ableism and discrimination that people with
23 disabilities face not only in our Commonwealth but across
24 the country and of course also across the world. And I'm
25 wondering if you can talk a little bit about how your work

1 has the potential to fight back against ableism and
2 discrimination, how you see that as part of your practice,
3 and if you can talk about whether or not you see abortion
4 bans as any kind of solution to the discrimination that
5 disabled people face? Thank you.

6 MS. CLEMENS: I think our role is to provide as
7 much education and resources to really attempt to minimize
8 discrimination and to fully educate all who are going to be
9 involved in the care of individuals with disabilities. In
10 my role as a genetic counselor and I know my colleagues
11 here at Magee, both genetic counselors and physicians, we
12 have been involved in educating a variety of medical and
13 community specialties. We have provided lectures in
14 medical schools, professional schools, colleges, even high
15 schools at times to make individuals aware of genetic
16 disorders, modes of inheritance, availability of genetic
17 counseling. But I still think that the decision of whether
18 or not someone wants to pursue pregnancy termination is a
19 personal decision which that individual needs to make based
20 on accurate information and their personal views.

21 REPRESENTATIVE BENHAM: Thank you. I appreciate
22 that. I agree that access to information and that
23 education is really critical to make sure that folks
24 understand the experiences of people with disabilities.
25 And as someone who spoke with a genetic counselor after

1 getting a diagnosis of Ehlers-Danlos syndrome I am really
2 grateful for the work that you and those in your profession
3 do, so thank you for your testimony.

4 MS. CLEMENS: Thank you.

5 MAJORITY CHAIRWOMAN RAPP: Thank you,
6 Representative. Representative Schemel.

7 REPRESENTATIVE SCHEMEL: Thank you, Madam Chair,
8 and thank you, Ms. Clemens. This is really just kind of a
9 question about within the realm of genetic testing, you
10 know, and maybe your familiarity with the work that's done
11 in ethics. You can tell me if this is just not a realm in
12 which you have much background, but is there anything for
13 which you would not test? I certainly understand the value
14 of a lot of the tests and there a lot of things that can be
15 done prenatally or to prepare a family, you know, even
16 postnatally for disabilities or other conditions that might
17 be genetic, but are there any tests that you'd say, you
18 know, we simply don't do that test prenatally because
19 there's no value to knowing that?

20 MS. CLEMENS: Well, long-standingly, testing
21 purely for fetal sex has been -- I'm just generally going
22 to say -- not performed. I don't see it so much as
23 requested more recently, but certainly much earlier in my
24 career among certain ethnic groups there may have been a
25 desire for, preference for a child of a certain gender.

1 There may not be a genetic test for everything.
2 There are some genetic tests for which there are very
3 specific protocols to follow. Let's think about something
4 like Huntington's disease or diseases in which there is
5 adult onset. There are a lot of ethical arguments about
6 whether prenatal testing should be performed for those
7 disorders kind of in the same context of genetic testing
8 pre-symptomatically is really avoided in minors.

9 REPRESENTATIVE SCHEMEL: So help me to
10 understand. You're talking about maybe a genetic marker --
11 and I might not be using the correct terminology -- but a
12 genetic marker for something, a condition for which someone
13 might have a higher percentage of having that may not
14 manifest until later in life, so there's really nothing to
15 be done prenataally --

16 MS. CLEMENS: Right.

17 REPRESENTATIVE SCHEMEL: -- or in their youth.
18 So why would you not test for something along those lines?
19 I'm curious as to that.

20 MS. CLEMENS: The argument has become maybe that
21 individual does not want that information.

22 REPRESENTATIVE SCHEMEL: Okay.

23 MS. CLEMENS: And that since it's a disorder
24 that's not going to have any implications well into
25 adulthood, should the decision of having that genetic

1 testing be left to that individual after birth as an adult?

2 REPRESENTATIVE SCHEMEL: So in terms of testing
3 like that, if a pregnant individual desired that testing,
4 does Magee do the testing or will they decline to do the
5 testing?

6 MS. CLEMENS: It usually involves a very
7 significant amount of counseling, risk-benefit analysis,
8 and lengthy discussion with the patient.

9 REPRESENTATIVE SCHEMEL: Okay.

10 MS. CLEMENS: It's also going to depend on the
11 circumstances and the family history and what the patient's
12 risk for the disorder is.

13 REPRESENTATIVE SCHEMEL: So in the end does Magee
14 make the call as to whether it will do the test or do you
15 for certain tests impose counseling requirements, but
16 ultimately it is the pregnant individual's decision?

17 MS. CLEMENS: It may be a blend of the pregnant
18 women's decision. It also may be a matter of is there a
19 laboratory that actually will perform the testing.

20 REPRESENTATIVE SCHEMEL: Is that because some of
21 the testing might be rare and laboratories don't do it or
22 because laboratories might have their own ethical qualms
23 about doing it?

24 MS. CLEMENS: The latter.

25 REPRESENTATIVE SCHEMEL: Okay. Good, thank you.

1 MS. CLEMENS: And I will tell you there are
2 situations in which we may work with an ethical team within
3 the University of Pittsburgh to try and make a
4 determination.

5 REPRESENTATIVE SCHEMEL: And I understand that
6 you're speaking to us -- so, forgive me, I understand you
7 don't necessarily speak for the hospital and you didn't
8 indicate you were an ethicist, so tell me if some of these
9 are uncomfortable questions or you say, look, that's just
10 not my realm, you need to talk to this other individual.
11 But it is curious to me that you make distinctions then or
12 it sounds like you do as to when someone, you know, a
13 pregnant individual might receive enhanced counseling
14 before receiving a test and others. So based upon what?
15 You know, based upon what criteria would someone qualify
16 for some sort of enhanced counseling? For example, I
17 guess, since we're talking about Down's, does Down's
18 trigger enhanced counseling or not or other conditions?
19 What is the marker that you would make that decision?

20 MS. CLEMENS: I mean, there are -- the genetic
21 counseling services available here at Magee are available
22 to any patient to explain all aspects of the testing.
23 Genetic counseling is a one-on-one individualized
24 appointment. And in all honesty, some patients may come
25 into the session and have a definitive thought or idea

1 about their perspective of testing and what they want to
2 do. And other patients may need more intense counseling.
3 We will raise issues related to risk-benefit from many
4 aspects.

5 One of the things I didn't mention is that
6 chorionic villus sampling and amniocentesis are procedures
7 that have a small degree of risk to the pregnancy involved
8 with them. What we quote here at Magee based on our
9 specific providers is about a 1 in 1,000 risk for
10 miscarriage. So in addition to just weighing that, some
11 patients really need to talk through the value of the
12 information that they are going to get, you know, how much
13 information do they want, what do they need to know, how
14 does it fit into their values and their ethics?

15 REPRESENTATIVE SCHEMEL: Okay. So from what you
16 are familiar with the way Magee at least handles genetic
17 testing, I believe the testing for Down's is fairly common.
18 Is there any enhanced counseling or what do you do with
19 counseling where the pregnant individual desires to abort
20 the child merely because the child has the disability of
21 Down's? Does that trigger any additional counseling or
22 not? Do other conditions may be just trigger enhanced --

23 MS. CLEMENS: No. I think any patient who
24 receives a diagnosis of Down syndrome receives -- we
25 provide, we abide by Chloe's law. Every patient receives

1 that Department of Health information. And we incorporate
2 what we know from imaging into our counseling in terms of
3 what might be anticipated in terms of healthcare for the
4 child. Some patients, this is a very simple or easy
5 decision. Many other patients -- and that's not a decision
6 to terminate. It's a decision to continue or to terminate.
7 And other patients very much struggle and may have several
8 conversations with a genetic counselor or lengthy
9 conversations.

10 One thing I'd like to comment on was there was a
11 statistic shown that 70 to 90 percent of patients who
12 receive a prenatal diagnosis of Down syndrome terminate. I
13 know that our experience at Magee is not nearly that high.
14 I think the last time we looked, it was probably in the
15 realm of about 50 percent, and just based on the number of
16 patients we are following, it may be even lower than that
17 right now. I also know that that statistic does vary
18 across the country. Some metropolitan areas have higher
19 rates. Other areas have much lower rates.

20 REPRESENTATIVE SCHEMEL: Very well. Thank you.

21 MAJORITY CHAIRWOMAN RAPP: Thank you,
22 Representative. Any other questions? Representative
23 Frankel, anything else?

24 Michele, I want to thank you. This is very
25 interesting. And you gave us some very good information.

1 I appreciate your time.

2 So, as we wrap up this part of these hearings,
3 we're just trying to cover all of our bases before we make
4 decisions. So I truly appreciate -- if we have other
5 Members who have questions, if we would email them to you
6 or contact you, if you could answer that, not that we have
7 any right now, but we do have several Members who are
8 joining us virtually. But I very much appreciate your time
9 in presenting to the Health Committee, very informative.

10 MS. CLEMENS: Thank you. And I really appreciate
11 the opportunity to just share information with you as well.

12 MAJORITY CHAIRWOMAN RAPP: Thank you. And,
13 Members, this concludes our hearing. Is it 12:00?

14 MS. METZLER: It's 12:00.

15 MAJORITY CHAIRWOMAN RAPP: Okay. So we're done
16 right about the time that we said we would be. And we'll
17 see you not week but the week after. And Representative
18 Frankel will be in touch of how we're going to proceed
19 either with Erika or yourself.

20 So thank you, Members, for being here. These
21 have been very informative. And I thank you for your
22 questions, Members, and thank you to all of our presenters
23 and staff who does tremendous work making all the copies
24 and working the computers for us, so I want to thank the
25 staff for all that they do for the Committee. So thank

1 you. Have a safe trip back home, and we will see you very
2 soon. And the meeting is adjourned. Thank you. Thank you
3 to members of the public also for tuning in.

4

5 (The hearing concluded at 11:59 a.m.)

1 I hereby certify that the foregoing proceedings
2 are a true and accurate transcription produced from audio
3 on the said proceedings and that this is a correct
4 transcript of the same.

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