COUNCIL OF THE CITY OF PHILADELPHIA

COMMITTEE ON PEOPLE WITH DISABILITIES

AND SPECIAL NEEDS

Remote location using Microsoft® Teams
Monday, December 11, 2023
1:00 p.m.

PRESENT:

COUNCILWOMAN KENDRA BROOKS, CHAIR
COUNCILWOMAN SHARON VAUGHN, VICE-CHAIR
COUNCILWOMAN JAMIE GAUTHIER
COUNCILMAN JIM HARRITY

RESOLUTION: 230593

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COUNCILWOMAN BROOKS: I understand that the state law currently requires that the following announcement be made at the beginning of every remote public hearing as follows: Due to the current public health emergency, City Council Committees are currently meeting remotely. We are using Microsoft Teams to make these remote hearings possible.

Instructions for how the public may view and offer public testimony at the public hearings of Council Committees are included in the public hearing notices that are published in the Daily News, Inquirer and Legal Intelligencer prior to the hearings and can be found on PHLCouncil.com. I now note that the hour has come.

Mr. Underwood, will you please call the roll to take attendance. Members that are in attendance,

please indicate that you are present when your name is called. Also, please say a few brief words when responding so that your image will appear on the screen when you speak.

THE CLERK: Councilmember Gauthier.

COUNCILWOMAN GAUTHIER: Good afternoon, Madam Chair and colleagues. Present.

THE CLERK: Councilmember Bass.

(No response.)

THE CLERK: Councilmember Harrity.

COUNCILMAN HARRITY: Good afternoon. I am present.

Sharon, you look too happy, my beautiful darling. I love the goodbye (inaudible) behind you.

THE CLERK: Councilmember Thomas.

(No response.)

THE CLERK: Councilmember Gilmore Richardson.

(No response.)

THE CLERK: Vice-Chair Vaughn.

COUNCILWOMAN VAUGHN: Good afternoon, everyone. And yes, Councilmember Harrity, I am still floating from Friday. You all made me feel very, very happy.

Good afternoon, Chairperson Kendra Brooks. Thank you for hosting this hearing for me. I am super ecstatic. And, Cody and family, thanks for being on here as well.

COUNCILWOMAN BROOKS: Thank you. A quorum of --

THE CLERK: And --

COUNCILWOMAN BROOKS: Someone say something?

(No response.)

COUNCILWOMAN BROOKS: Thank you. A quorum of the Committee is present and this hearing is called to order. This is the public hearing of the Committee of People with Disabilities and Special Needs regarding Resolution No. 230593.

Mr. Underwood, would you please read the title of this legislation being considered today.

THE CLERK: Resolution No. 230593, authorizing the Committee on People with Disabilities and Special Needs to hold hearings regarding the issues, challenges and misdiagnosis for children and their families dealing with Ehlers-Danlos syndrome.

COUNCILWOMAN BROOKS: Before we begin to hear testimony from witnesses we have for today, everyone that has been invited to the meeting to testify should be aware that this public hearing is being recorded. Before the hearing is public, participants -- because the hearing is public, participants and viewers have no reasonable expectations of privacy. By continuing to be in this meeting, you are consenting to being recorded.

Additionally, prior to recognizing Members for questions or

comments they have for witnesses, I will note for the record at this time that we will use the chat feature available in Microsoft Teams to allow Members to signify that they wish to be recognized. In order to comply with the Sunshine Act, the chat feature must only be used for this purpose.

Are there any Councilmembers that would like to speak before we turn to witnesses?

COUNCILWOMAN VAUGHN: Madam Chair, I would like to speak.

COUNCILWOMAN BROOKS: Thank you, Councilmember Vaughn. Can you please proceed.

COUNCILWOMAN VAUGHN: Yes. Thank you, Madam Chair. Let me begin by taking -- thanking you and the Committee for People with Disabilities and Special Needs for hearing this resolution to help bring awareness to the Ehlers-Danlos syndrome, specifically regarding the

issue of frequent misdiagnosis of this disorder.

I also want to make one thing clear. This is not a call-out or attack on anyone or any organization. We are simply trying to enhance the public's knowledge of such matters that without proper perspective and consideration have the potential to negatively impact the quality of life of some of our most valuable families and populations.

We've all heard stories about medical misdiagnoses from others we know or even on the news and how those misdiagnoses upended people's lives. As I previously stated during my introduction of this resolution, a medical misdiagnosis of any kind can have serious life-altering implications such as receiving appropriate treatment or delayed care. But when it is something as rare and as complex as EDS which can yield symptoms, there would be

similarities to bruising and be misinterpreted as physical abuse, proper education, accuracy and competency to make all the difference.

I appreciate this Committee for convening this hearing and I look forward to seeing the results of these important conversations. Thank you, Madam Chair.

COUNCILWOMAN BROOKS: Thank you so much, Councilmember.

Mr. Underwood, would you please call the first panel we have to testify this afternoon on Resolution 230593.

THE CLERK: The first panel includes Sara Enes, Chief of Staff of the Philadelphia Department of Public Health and Dr. Michael Holick, Professor of Medicine at Boston University School of Medicine. We will start with Sara Enes.

MS. ENES: Good afternoon, Chair --

COUNCILWOMAN BROOKS: Good --
MS. ENES: -- Brooks. Sorry. Go ahead.
COUNCILWOMAN BROOKS: Good afternoon. Are you connected and ready to proceed?
MS. ENES: Yes, I am.
COUNCILWOMAN BROOKS: Please state your name for the record and proceed with your testimony.
MS. ENES: My name is --
(Background interruption.)
COUNCILWOMAN BROOKS: Councilmember Harrity, can you put your phone or computer on mute?
COUNCILMAN HARRITY: Sorry.
COUNCILWOMAN BROOKS: Thank you. Sorry. You can please proceed.
MS. ENES: My name is Sarah Enes.
COUNCILWOMAN BROOKS: Can you please proceed with your testimony?
MS. ENES: Sure. Good afternoon, Chair Brooks, Vice-Chair Vaughn and members of the Committee

on People with Disabilities and Special Needs. As I stated, my name is Sara Enes. I'm the Chief of Staff for the Philadelphia Department of Public Health. I'm here testifying on behalf of Dr. Cheryl Bettigole, Health Commissioner who is currently out of town, and we thank you for the opportunity to testify on Resolution 230593.

In recent years there have been some well-publicized concerns about children with underlying medical disease being mistakenly reported to authorities as child abuse. Reports of child abuse have been disproportionately filed against parents of color, particularly Black parents, resulting in high rates of family separation that are devastating for parents and children.

Concertedly, death and near fatalities among children due to abuse or neglect has risen substantially in recent years in

Philadelphia. So we need to focus on an accurate diagnosis to avoid both overreporting and underreporting of child abuse and neglect, while also addressing the systemic bias used that has historically impacted people of color seeking medical care.

Philadelphia is lucky to have some of the top pediatric specialists in the country, including some of the leading child abuse specialists. Specialists such as those at Children's Hospital of Philadelphia and St. Christopher's Hospital for Children could help to educate physicians and other healthcare professionals in Philadelphia to ensure that they have the most up-to-date information on how to best detect cases of child abuse without overreporting or misdiagnosing. And all of us need to continue to educate ourselves on these issues, which are critical for the health of our children and the well-being of their

families. Thank you again for this opportunity to provide testimony on this important issue.

COUNCILWOMAN BROOKS: (Muted).

THE CLERK: Councilmember, you're muted.

COUNCILWOMAN BROOKS: Thank you so much, Ms. Enes.

THE CLERK: Great. Next is Dr. Michael Holick.

DR. HOLICK: (Muted).

COUNCILWOMAN BROOKS: You're muted, Mr. Holick. Good afternoon. Are you connected?

DR. HOLICK: Good afternoon. My apologies.

COUNCILWOMAN BROOKS: Can you please state your name for the record and proceed with your testimony.

DR. HOLICK: Sure. It's Dr. Michael F., as in Francis, Holick, H-o-l-i-c-k. I'm a Professor of Medicine, Pharmacology, Physiology and Biophysics and Molecular Medicine at Boston University School of

Medicine. I thought I would give you a very kind of overview about what EDS is, my experience with EDS and then the misdiagnosis and my opinion related to EDS and issues of child abuse.

And to begin, I'm very concerned about child abuse. I am considered to be a reporter for child abuse and I would never permit a family of being evaluated by me if I knew that they were committing child abuse. So EDS is a genetic disorder. It's autosomal dominant, which means that 50 percent of offspring will acquire this genetic disorder.

This genetic disorder affects your collagen elastin matrix, which is basically the scaffolding of your entire body, and this can explain why blood vessels are more prone to bruising and there's marked increase of fracture because the bone contains a major -- the major component is collagen elastin along with your

mineral content.

I've been seeing children and adults with EDS since 1978 when I became Assistant Professor at Harvard Medical School and I've been writing about EDS for that period of time. So here are now some of the consequences and why it's so critically important to make this diagnosis as soon as possible. It's stated in the 2017 Consensus Conference, meaning that I guess the recommendation suggests that it's (inaudible), they say you can't make a diagnosis in a child until they're 5 years of age because EDS is associated with increased joint hypermobility. But of course, this defies logic because it's an autosomal dominant genetic disorder. And so, the infant acquires it from mom or dad in utero.

And so, here are some of the consequences: For example, if an infant is bruising easily, that's

because they have what's called capillary fragility. And it's important to make this diagnosis because I warn parents that if for some reason if they're handling their infant and bumps head on, say, the crib, they should be taken to the hospital because they're more likely to have capillary fragility and have a brain bleed and cause subdural hematoma that can have serious consequences, including paraplegia and even can cause death.

It also causes gastroparesis. Often infants with this genetic disorder are constantly spitting up and they're misdiagnosed as having gastrointestinal reflux. When, in fact, what's happening is that their stomach -- because they're more elastic, blows up like a balloon and then collapses and as a result, they spit up. And the simple fix, believe it or not, is simply giving smaller feedings multiple times of the day in

order for them to get the amount of nutrition that's required.

They also have bone fragility. It's well-documented in the literature that animals are at 10 times higher risk of fracture for the same amount of trauma that would not cause a fracture in an adult (inaudible). We published two papers. The first paper, 72 cases of infants that were thought to have been abused, they had presented with multiple fractures. 93 percent of them I saw at least one of the parents, and 64 percent I had the opportunity to see the infant and made the diagnosis of Ehlers-Danlos syndrome, hypermobility type.

The other 7 percent by the way which is much more common, especially of people of color, is vitamin D deficiency rickets. Also, they have joint hypermobility. The joints can be popping in and out. And often I will ask the parents, especially the

mom who's feeding the infant, does your infant love to kind of stretch his back almost like into a C-like position and they often say yes. And the reason is because they have such flexibility of their ligaments, including their spine.

Often when they're picked up, their joints click. Now, normally a pediatrician not having any experience in this area will just say, well, that's just normal. It's not normal. This is caused by the laxity of the ligaments of the joints. And so, parents will tell me that they're picking up their infant, that they can feel the ribs click, they can feel the shoulders click, and all of this is related to this genetic disorder.

There's a recent publication that's confirmed my observation out of Holland where a family had been accused of child abuse of their very young infant, they had a 2-year-old

at home. And even though it was an expertise hospital in child abuse, they equivocally concluded it was due to child abuse, and the infant and other child were taken away from the family for a year. They finally found a pediatric endocrinologist with a specialty to appreciate Ehlers-Danlos syndrome in infants and he informed the court of this information and as a result, the children were returned to the parents.

So this is a critically important issue for parents because these infants have extremely fragile skeleton. And I reported some infants having up to 32 fractures at the age of 4 to 6 weeks, right, without a bruise on the body, and yet it's immediately concluded that if you have a genetic test for brittle bone disease, osteogenesis imperfecta, if it's positive, then you have the explanation, they send

the infant with the parents home.

But if it's negative, then they're automatically accused of child abuse and as a result, their children are taken away from them and they go through an enormous amount of horrific grief by not being able to -- a young woman breastfeeding her infant, for example. So from my perspective, incredibly important that this diagnosis be recognized legislatively, and that should be considered in the differential diagnosis of infant fractures or infant bruisability, including brain bleeding like a brain subdural hematoma.

COUNCILWOMAN BROOKS: Thank you so much, Dr. Holick.

Are there any questions or comments from members of the Committee for this panel?

(No response.)

COUNCILWOMAN BROOKS: There being none, Mr. Underwood, will you

please call the next panel to testify for the resolution.

THE CLERK: The second panel includes Cody Carter, Sr.; Erica Palmer; Donna Palmer; and Andre Dover. We will begin with Cody Carter, Sr.

COUNCILWOMAN BROOKS: Good afternoon. Are you connected and ready to proceed?

MR. CARTER: Yes, yes. Can you hear me?

COUNCILWOMAN BROOKS: Yes. Can you please state your name for the record and proceed with your testimony.

MR. CARTER: Hi. I'm Cody Carter, Sr. And just to paraphrase because we went through so much that it will take longer for this here for us to really tackle everybody, so I'll summarize. I am a parent who went through this with our son Cody Carter, Jr. Back in 2020, we had a 3-month-old that was projectile

vomiting and we were just concerned parents taking our son to the emergency room, and we had no idea what was going on.

Get to the emergency room and without finding out any medical history between me and his mother, asking any further questions or even running any tests, they assumed child abuse from the very beginning. From that moment on, we had no voice in the situation. It went from that to detectives coming to the hospital, to phones being taken, to me and Erica being put in DHS going through supervision, DHS supervision, splitting up our home, taking our son for a year all from a hospital visit.

And we remain -- we were stating like we just wanted to know answers, we just wanted to know answers. And nobody could give us any answers because everybody had all the conclusions. And this is -- it's hard to relive this.

MS. PALMER: Very painful.

MR. CARTER: Like I said, just showing up in the hospital. Could you imagine just showing up to a hospital? The next thing, you know, you're in the hospital for 48 hours, your son is sick and you got detectives coming to you, talking to you like you're just a hardened criminal. Telling your lady, yo, just testify that he -- just say that he assaulted your son, just trying to coerce her to go against me divided our family.

I had to move. I had to do all of this stuff. Mind you, we still have an infant. She's still recovering from having a baby and all of this happened and our son was taken for a whole year. We end up in DHS. And the DHS system is a whole 'nother horrific but we won't get into that.

But we had went through so much trauma, only to get our son back

and find out that he was born with a condition called EDS that I have, I suffer from EDS. His mother has EDS. We were just always wanting more answers and we always knew it was never no abuse. We remained steadfast on that, that we never abused our son. He never had a bruise. He didn't show no signs of distress. Nothing showed abuse. All we asked for was just another expert opinion, and everybody just knew the answers, the detectives, the DHS worker. Even the people at the hospital didn't know my last name, but they knew I hurt my son.

And it's like, this is the reality of what's going on, on a daily basis in Philadelphia. And I can't speak on other cities, but imagine what families are going through when they just are trying to figure out what's going on with their child and they are entering into this horror. And this is not nothing to

play with.

These are accusations that should not be drawn upon assumptions. We should be out here getting tests done. Make sure you rule out everything before you just jump to conclusions. I think that with these type of accusations it's that serious because we know that there's people in jail for child abuse. There's people that's in jail for child abuse.

So if you say that somebody is abusing a child and in our situation, they said our child was a near fatality. So you're telling me my son was attempted murdered, you're saying my son was almost killed but you didn't even lock me up. When they sent all this stuff to the DA, the DA sent it back and said it's nothing here. So it's like -- I'm like, yo, I'm sitting here telling y'all, yo, it's nothing here.

MS. PALMER: Medically there's

something wrong.

MR. CARTER: So I'm just like, yo, if all these signs are showing you that it's nothing here, just please run the tests before you jump to conclusions. Because you know like I know, you can't do nothing with child abuse on your record. You can't work at McDonald's with child abuse on your record because you can't be around children, correct. So why are we jumping to these types of conclusions, putting people's lives at danger, breaking people's homes up, telling significant others, yo, just lie.

Detectives were telling her to just lie, just come up with a false statement so we can end this case. So this is what's going on, on a daily basis, and this is not right. And I refuse. I said I am not laying down. I'm going to fight. Y'all gave me my son back, but this is not the end of this because it's more to

this, and it's like so many families that's affected by this on a daily basis.

I thank God for people like Ms. Sharon who's my mentor. I thank God for Derek Green. These people have gotten behind me. Dr. Holick, thank God for him. We flew to Boston to get his expertise and he ran all the tests. I just thank God for people because it's so many families that's silent that have no voice out here that's going through this as we speak, daily basis. And it's like we can't do this because these are accusations that are destroying families.

And imagine if we didn't have the strength to get back together. There's people that's making them hate each other. They made me and her hate each other. They made our families hate each other because the DHS worker was putting one thing in her ear and putting one thing in my

ear. This is what the DHS system is about. This is what the child welfare system is about. Their whole model is we're here to rebuild families. We're here to restore families. They're doing the exact opposite, the exact opposite.

And when I reached out and I spoke on all of this, I even reached out to Ms. Kimberly Ali. I wrote letters to everybody to inform them what's going on in these facilities. And guess what, all my frustrations and all my concerns fell on deaf ears. But thank God for people like Ms. Sharon who got behind me. Thank God for people that heard me. Because think about the families that's out here getting affected by this. They just get their kids back and move on with their lives.

Child abuse is not something you can just put on people. All I want is for us to change the system. Just run tests, just actually find

out the history on people. Actually when they're in the emergency room, rule out everything before you jump to these conclusions because child abuse is the equivalent of rape and all this other stuff. It's the worst thing to have on your record and it's destroying people. Thank God I'm strong and I'm able to move forward with my life and still stand tall, but it's so many families that don't have that fight.

I read numerous stories of people who committed suicide behind this type of stuff because of these type of things, families broken up and guys locked up. I didn't get to that extent, but it's like come on. And that shows you -- that was the answers right there. If you have all the answers and say, yo, somebody almost killed their child, while wasn't I even locked up.

I'm telling these workers I didn't hurt my son. They took my

phone. They were only supposed to have my phone for 48 hours. I'm sitting in the hospital just a concerned parent. The detective took my phone and kept my phone for a month. The detective told me, I know you hurt your son. How do you know this? You don't even know me. And you're telling me you know that I hurt my child. And this is what families are going through. It's trauma. It's trauma. Just talking about this right now is bringing back so many skeletons because this is hard.

When you just want to be a loving, concerned parent and we're just taking our child to an emergency room and we end up going through all of this for what. So I'm just here and I'm going to keep fighting. And obviously, I got this -- I just want tests run. Just rule out everything before you jump to conclusions because at the end of the day, it's

families' lives being affected on a daily basis. And it's a lot of families out here that's affected by this.

And me doing my research on EDS, 1 in 4 families is dealing with EDS as we speak. So many families are going through this and I done read so many stories, met so many different people that just don't know what to do. Nobody has this platform. Nobody knows how to reach out to people of your caliber. So think about how many people that's really going through it out here.

So I just want us to change the system in Philadelphia. Just run more tests. You know, educate these doctors so they know what's going on. And just rule out everything before you jump to conclusions. That's all. Thank you.

COUNCILWOMAN BROOKS: Thank you so much, Mr. Carter. I hear you, I hear you.

Mr. Underwood, who --

THE CLERK: Next is Erica Palmer.

COUNCILWOMAN BROOKS: Erica, can you state your name for the record and then proceed with your testimony please.

MS. PALMER: Sure. I'm Erica Palmer. Cody Carter, Sr. just spoke a little bit on what we went through. I'm going to add a little extra and I'm praying for the best of this Committee. Honestly it's going to be very hard for me. It is very traumatic. And every time it brings back tears because we're reliving it by trying to fight for others so it doesn't happen to them.

When our son was 3 months old, we had to take him to a pediatric wellness visit. Everything was fine. We addressed all the concerns that we had, which honestly was everything Dr. Holick just brought up. Our son was projectile vomiting. Projectile

vomited there at the appointment. We were told a GI bug was going around.

He had a C-spine curvature every time we sat him down on the couch, and we were told that was related to GERD as with infants. I'm a registered nurse here in Philadelphia and I did let her know, the pediatrician, that it is not when he eats. It's not consistent with feedings for him and it's just random when he would projectile vomit. And she just said to keep an eye on it. If need be, that it would fall on the lines of GERD for infants.

He had an enlarged head circumference when we went there, was the only abnormality for her so she scheduled an ultrasound. I then put that ultrasound in following up with them that coming week because I did have work and I did want to be present for that. I'm a weekend nurse. I only work Saturday, Sunday. I'm home with the kids during the

week.

So I went to work, I came home and I found out that he did vomit one more time for Sr. while he was watching him and then he projectile vomited all over me. I did every step possible to try to get my son help and care. I called the on-call nurse. I called -- they called the on-call physician. It took at least an hour-and-a-half or two to get back to me.

We decided to speed up the ultrasound. We took him down to world-renowned CHOP. CHOP has their own EDS division in there, which we did not know of at the time. And just like he said, our son was taken down there and our world was thrown for a loop. It was trauma from there on out.

They did the ultrasound of his head. They said they saw subdural hemorrhages. So then they decided to do full body scans where they found

fractures. They called them buckle fractures of his tidbits. We had an orthopedic physician come in and say, he's going to need bilateral casts. Then rescinded everything that he just said and said, I'm sorry, that's not true, he does not need casting. He didn't even have a tidbit fracture. It was just a buckle at the end of the epiphyseal plate. So that didn't happen.

He had to put a shunt in his head to drain the subdural fluid. They didn't know if it was blood. They didn't know if it was cerebral. They didn't know anything. They didn't tell us specifically what was going on and why he needed a subdural shunt. However, because we were thrown into this traumatic loop, we had detectives coming. We had our son who we believe is near fatality that needs to have a shunt placed.

He had a shunt placed. It literally was occluded within a week.

He did not need an internal shunt placed. All he had to do was external. There are steps that need to be taken that need to be like an algorithm inside a hospital that is not just thrown to this child abuse, because then the scan doctors came instead of consulting the EDS group, and everything could have been handled right there with the EDS group.

Instead we had to talk to Scan. That's thrown to DHS. And just like he said, DHS turned us against each other. We were separated for a whole year. Throw in COVID with that, I'm wrapping up bodies day-to-day because I'm a registered nurse and I'm going hospital-to-hospital to care for others. I couldn't even know about the care of my own son because DHS would not let me reach out to kinship who was caring for him, and I couldn't reach out to him because

it's not an emergency and it's not my scheduled days to talk to my son.

So we want answers. We want change for everybody else so that they do not have to go through what we went through and everyone who's going through it, we will continue to fight and we're asking for everybody on this board their help to change to put things in place, so that when kids and family members come into these emergency rooms and don't have answers, every possible medical diagnosis is ruled out, every single one. Not just it's brittle bone or shaken baby, not just those two. There are other things that can be tested for. EDS needs to be a part of that. And I'm just asking for help and I'm asking for help please.

COUNCILWOMAN BROOKS: Thank you so much, Ms. Palmer. Thank you for sharing your testimony. I know it's really hard for your family to have to relive this experience all

over.

MS. PALMER: Thank you.

THE CLERK: Next is Donna Palmer.

MS. PALMER: Hi, I'm Donna Palmer.

COUNCILWOMAN BROOKS: Thank you. Can --

MS. PALMER: I'm the grandmother and the mother. It is extremely difficult. I had to witness the worst horror. I'm a registered nurse of 46 years. I raised this daughter. I know Cody was an excellent father and I had to witness the most traumatic and horrible feeling. Not only at this hospital that I feel betrayed me because I worked 23 hospitals and I always think they're going to do the best for everyone.

Not only did this hospital betray us by assuming, but then this child protective services was a debacle. It was the most horrendous

thing, the most unprofessional. It was almost sinister. It was as if we were in some freaking movie, some horror film. It was the worst thing. And of course, on top of it we had COVID. We couldn't get a hold of anyone.

I was concerned of the -- I don't know if Dr. Holick understands that or heard this, primal wounds. If a child is not with their mother in the beginning, it's all kinds of psychological problems that happens after that. I also know he did not need a shunt. It could have been a simple aspiration.

There were so many things. I was holding the baby. He was perfectly happy. They're telling me he has broken bones. I'm a nurse. I know when somebody's got a fracture. You don't lay there and be happy and laugh. There are so many things that have to be stopped.

I also want this Committee to

know while it's in my brain right now that Dr. Holick has enough samples, all he needs is some money so we can get that genetic test that can be drawn in every ER for every kid that's suspected of child abuse and if it comes up with EDS, but he needs the money to be able to get that genetic test figured out or whatever it is that has to be done. But that's the stuff that has to get done first.

Never once was it asked of my daughter or CODY, does your wrist bend back, is their sleeves too long, specific things for EDS that Dr. Holick sent out and we had a sheet that we filled out. And I remember saying to Erica, I've never seen an assessment with questions like this, what are these questions. They had nothing to do with medical, but it all had to do with what EDS does with the individual, palpitations, different things that

you would never think about because you lived with it. You just grew up with it and you don't know you have it.

I have EDS. She has EDS. Cody has EDS. So of course, both of their children have EDS. So it's just -- I am thankful that you're listening. I do want you to know that I don't want a single mother or father to ever have to go through this again. If there's anything we can do to prevent it and stop it, especially with the folks with a little more melanin in their skin. Vitamin D, she was low. CJ was low. It's paramount with the bones that Dr. Holick said. It's all -- it just needs to be stopped and corrected and put into place so that -- I also know child abuse. I've seen it. It's horrible.

I don't want perpetrators to have their kids back, but I don't want innocent parents being accused

of this and they -- somehow we have to figure out how to figure out both. So that's my testimony.

COUNCILWOMAN BROOKS: Thank you so much, Ms. Palmer, for your testimony. You --

COUNCILMAN HARRITY: I --

COUNCILWOMAN BROOKS: -- left us some really good points for us to follow up with, so thank you so much.

Councilmember Harrity, can you hold on one second. We're going to open it up for questions for the Committee.

THE CLERK: The last witness is Andre Dover. I'm not sure if Andre's here.

COUNCILWOMAN BROOKS: Is Mr. Dover available?

(No response.)

COUNCILWOMAN BROOKS: Do we have a way to contact Mr. Dover, Mr. Underwood?

THE CLERK: Dwayne, did you have a way to contact Mr. Dover?

UNIDENTIFIED SPEAKER: I have reached out to him and I have not heard back. Did hear from him over the weekend saying that he was interested in testifying. He has all the information to be in the meeting.

COUNCILWOMAN BROOKS: Okay. Well, we'll move forward.

Are there any questions or comments from members of the Committee? I see Councilmember Harrity has his hand raised.

COUNCILMAN HARRITY: Thank you, Madam Chair.

COUNCILWOMAN BROOKS: Councilmember Harrity, I see Councilmember Vaughn put her hand up. Since she's the bill sponsor, can she start --

COUNCILMAN HARRITY: Absolutely. Absolutely.

COUNCILWOMAN BROOKS: -- and you follow right after her?

COUNCILMAN HARRITY: Absolutely.

COUNCILWOMAN BROOKS: Thank you.

COUNCILWOMAN VAUGHN: Thank you, Madam Chair.

Cody and family, it's traumatic to hear your testimony and that's why I pursued this with such diligence. I am happy that we are able to put this information out here to the world so that no other parent has to go through what you went through and/or still going through. Because once we go through trauma, it has a ripple effect, you know, and we never know where the rings of the cycle ends.

So thank you for bringing this to our attention and we will definitely continue to work on this to make sure that no one has to suffer the way that you have ever again. I cannot imagine the separation issues, Donna, of having a new baby and not getting to spend that quality time in the very

beginning with your newborn child.

And to say that this is happening over and over again is definitely something that we have to put to the forefront of the medical society as well as citizens of Philadelphia. We need to make sure that they understand that this does exist if they're ever going through this type of situation.

Thank you, Madam Chair.

COUNCILWOMAN BROOKS: Thank you so much.

Councilmember Harrity.

COUNCILMAN HARRITY: Yes. Thank you, Madam Chair. Thank you, Co-Chair Sharon Vaughn, for putting this in because this is the first I've ever heard of this.

And you know, I understand what you guys kind of are going through. I lost my first child because of a genetic defect that my wife had that was not tested for. And then my second son was born with

(inaudible) cardio -- was born with a genetic disease where his immune system would shut down, so I spent a lot of time at Children's Hospital of Philadelphia. Thank God the genetic thing he had, you grow out of it by the time you hit 8 if you catch it at an infant. If you get it as an adult, it never goes away.

But, you know, it's just the fact that you brought your child to the hospital trying to do the right thing by him. And as a parent, I know you were scared, you didn't know what was going on, you just wanted help and they turned around and made you into something that -- I couldn't even imagine somebody accusing me of something like that. Like I said, I had to take my son once a week, sometimes twice a week to Children's Hospital. I know the way I am if they would have accused me of that I probably wouldn't have handled it like you did, Cody. You're a

gentleman.

But my question is for the doctor. Doctor, what would it entail to make this part of protocol at a hospital to actually check? Before we accuse somebody of child abuse, we should be checking for every possible thing. You know, infants can't tell you what's wrong with them. So by doing tests, is there a huge cost for this? What are the main issues of why they're not doing something like this?

DR. HOLICK: Thank you for the question. I have over now 400 families that have contacted me. I have seen well over 100 families and it's the same story. A young family brings their infant in because of coughing, takes an x-ray, finds multiple fractures, negative test for bone disease, they're a child abuser. And just as you've heard from this family, it's truly devastating.

I just testified for a family,

if you can believe it, in Wisconsin where the father was charged with murdering his infant son. They had twins, a twin girl and infant son. The infant son actually died of pneumonia but because he had all these fractures, they said obviously they were beating both him and the infant daughter. I testified and others did as well, and all the charges were dropped. I can tell you horror stories.

Here is your problem, right: I was a guest of honor because of my expertise in vitamin D to CHOP. But unfortunately now because of that Consensus Conference of 2017 where they say you can't make a diagnosis in a child until they're 5 years of age, right, it defies logic, right. You already heard from the family that the infant was spitting up a lot, has fractures, bruising easily. You need to know this diagnosis at birth. And the best way to do this

is you need to educate actually primary care docs, pediatricians, obstetricians so that the mom, the pregnant woman is known to have this genetic disorder and, therefore, the infant has a 50 percent chance of having it.

By the way, EDS causes high risk pregnancy that is often missed by the obstetricians. And so, the first thing we need is a teaching to pediatricians because unfortunately because I've been doing this and I've challenged the child abuse community, they actually rose up and started sending emails to my hospital, including Dr. Lori Frasier from Hershey, and they ultimately conspired and got me fired as a physician at Boston Medical Center, right.

And the reason is pediatricians have never been taught this. They've been taught you can't make a diagnosis until they're 5

years old. So as a result, they ignore this completely. They need to know, make the diagnosis in the mom and dad. Family history is critically important at the time they're in that emergency department with a child that has easy bruisability, a bleed in the head or fractures, right. And then following -- now, the question about how do you make the diagnosis, right. It's a medical diagnosis. There is no genetic test.

And I have a genetic program at Boston University School of Medicine, so I remain Professor of Medicine because my dean believes in academic freedom. And as a result, I have over 400 DNA samples ready to go. We had a recent case where a mom in utero, she had EDS. In utero her son had fractured both arms, both legs, most ribs. In utero her son had 23 fractures. Can you imagine what would happen after birth.

They showed that the child has 23 fractures and they did genetic testing for brittle bone disease and it came back negative. But guess what, right? It's in utero so they knew something was going on, so I did whole genome sequencing on the entire family. We published this and identified a new gene responsible for in utero fractures. So this in itself should make pediatricians alert that you cannot any longer say an infant with multiple fractures or bleeding could only be due to osteogenesis imperfecta or child abuse because I've already identified a third cause, and that means there's many more out there.

But if I could raise $1 million, that's what we need, we could actually do whole genome sequencing on our 400 samples and I think we would be in a very good position to be able to develop a genetic test.

COUNCILMAN HARRITY: Okay. So right now there's no genetic test that can be done?

DR. HOLICK: Correct.

COUNCILMAN HARRITY: Okay. Got it.

DR. HOLICK: And that's the problem, right. And so, you have to make the diagnosis based on medical history and family history, and pediatricians don't do that.

COUNCILMAN HARRITY: In the case of my wife it was something they didn't test for unless you were already high risk. But again, if they would have tested for it in the beginning, they would have figured out that she had a cardiolypic(ph) and maybe things would have been different.

So again, my heart goes out to you guys. Again, Cody, I couldn't even imagine. I would go bananas. My colleagues know me. They probably would have taken me out in handcuffs.

But thank God you had the calm and coolness to keep your head and stay in there because they would have turned it into something else. So I appreciate you testifying today. I know this must be hard.

It had to be a strain on the family, especially if they're pitting both of you against each other. It's not right, man. The whole idea is to keep families together.

MS. PALMER: It divided our families.

MR. CARTER: That's a whole 'nother issue. That's a whole 'nother issue. The DHS system is a complete joke, so that's something we all need to talk about on another date because that system is terrible and their workers are the worst.

MS. PALMER: And they're still there. And they keep trying to bring the ones back that were doing part -- and he wrote a letter to, I'm sorry, Ms. Kimberly who did not respond --

MR. CARTER: Nobody responded.
MS. PALMER: -- to the letter, and we've heard that this person has been asking (inaudible) to come back, although she was not professional whatsoever and the one she had in position was not professional whatsoever.
MR. CARTER: So I think that's something we all need to look at, because with you guys being in -- with you guys being in the position you guys are in, I'm sure a lot of things -- a lot of resources are going to these different programs, but I think y'all need to look at the programs and make sure that these programs are effectively using the funding that they are getting and actually having workers to do their job correctly because at the end of the day, they're a part of the problem.
It starts in the hospital, but then it goes to the social workers

and it all creates one big wedge of problems so --

MS. PALMER: Caseworkers.

MR. CARTER: Or caseworkers, social workers, all of them are the same. They're all a part of the problem. And we ended up getting a second opinion by going to St. Chris. Now, here's another kicker that as my lady told you that they put a shunt in his head, right. So the same doctor that put the shunt in his head, we asked him, well, what happens as he grows and stuff like that. And the doctor says, oh, nothing happens, he'll be fine.

Then we end up getting another opinion later down the line and ended up going to St. Chris, who actually is a great hospital, complete different experience from CHOP. And a doctor there removed the shunt. My son's 4 now. He's only getting taller and getting bigger. So you mean to tell me that that shunt was

just going to not grow and he wasn't going to have a bunch of different issues in his life. So think about that. He could have ended up handicapped by having a shunt that he wasn't even supposed to have. So these are all bigger issues.

And if we didn't fight and do that, he would still be walking around with a shunt at 4 years old right now sticking out the side of his head that he didn't even need. But it was removed thank you to St. Chris, so you got to think about that as well. Think about the families that's just being told, oh, everything will be fine. No, everything won't be fine because the kid never needed surgery.

So you got my son under the knife, got his head all messed up. Thank God he fully recovered, he's thriving. But come on. This can't be the normal. It can't be.

COUNCILMAN HARRITY: Thank you

again, my man.

COUNCILWOMAN VAUGHN: I --

COUNCILMAN HARRITY:

Appreciate you, Cody.

COUNCILWOMAN BROOKS:

Councilmember Vaughn, you have comments?

COUNCILWOMAN VAUGHN: I just want to know, I see the Commissioner is on the line with us. Is she able to respond to any of this stuff or give us some answers as to how this happened and if procedures are put in place for people to identify this disease so that no one else that is reported to DHS will have to go through this again?

COMMISSIONER ALI: So good afternoon.

COUNCILWOMAN BROOKS: Good afternoon, Commissioner.

COMMISSIONER ALI: I'm Kimberly Ali, Commissioner for the Philadelphia Department of Human Services. Thank you for inviting me

today. And first, let me just say to the Carter and the Palmer family, I certainly sympathize with the trauma that your family suffered.

I will say this to you, Councilmember Vaughn, in terms of the systems that are in place, child protective services workers or the Department of Human Services workers rely heavily on the medical community, heavily on the medical community. Our social workers are not experts in terms of medical diagnosis, medical treatment. We follow what is written, what is prescribed by medical physicians. Therefore, treatment, diagnosis, education, anything we can do in terms of knowledge and understanding rest with the medical community in order so that reports can come to DHS appropriately.

Given that apparently a report came in reference to child abuse, any time a report comes in reference to

child abuse, particularly physical child abuse, DHS consults not only with our nurses, we have 18 nurses that are on staff with the Department of Human Services because of the complexity of medical diagnosis in young people with special medical conditions who work in concert with our two major hospitals, which is Children's Hospital of Philadelphia as well as St. Christopher's Hospital and the medical personnel in order to determine the diagnosis as well as the treatment for young people. And so, getting the word out, educating in reference to that is critical so that our social workers too can be informed.

COUNCILWOMAN VAUGHN: I thank you, Commissioner. But based on this case, has your team or your employees been informed that this is a disease that does exist? And I understand that you rely heavily on the medical field and their evaluation of the

patient, but now that we are somewhat aware that this exist is there a way that your team can say to the doctor or the nurses can say, listen, let's rule out EDS before we take the next step?

COMMISSIONER ALI: I cannot tell them before we take the next step. However, we certainly could have conversations, our nurses in particular. Because what we find is medical personnel respond well to other medical personnel, can certainly have a conversation about whether or not there is some other plausible reason as to whether or not young people have fractures or bruises. And so, yes, we can elevate that discussion.

COUNCILWOMAN VAUGHN: Thank you, Commissioner.

Thank you, Madam Chair.

COMMISSIONER ALI: Thank you.

COUNCILWOMAN BROOKS: Thank you. Thank you, Madam Commissioner.

Thank you, everyone.

That concludes the panels for this resolution. We will now begin to hear from individuals who wish to provide public comment and we ask that you please keep your comments to no longer than three minutes.

Mr. Underwood, would you please read the name of the first person registered for public comment.

THE CLERK: There is no one registered for public comment.

COUNCILWOMAN BROOKS: Okay. Are there any questions or comments from any members of the Committee?

(No response.)

COUNCILWOMAN BROOKS: I just want to give a few final words. I said I wasn't going to speak on this, but I worked 17 years with Easterseals of Southeastern Pennsylvania and that's when I first became familiar with this diagnosis and have worked with several families with children that are trying to

include them in day care or recreational programs, and we had a type of notification on our records and all the staff members had to be aware because bruising is easy, bleeding is easy and brittle bones is easy.

I think the same notification that we need to give for providers in order for young people to live and thrive as they get older is the same consideration we need to take when they're infants and we're trying to navigate the system. So my heart goes out to this family. I hope you guys come and are able to find a sound resolution to this so this does not happen to anyone else. I guess Councilmember Harrity and I will still be around to help support this after Councilmember Vaughn is in retirement, so please stay in touch with us.

Thank you so much, Dr. Holick, for your work in bringing recognition

to this. Thank you, Commissioner Ali, for coming on speaking on behalf of DHS.

There being no further questions from members of this Committee and no other witnesses to testify, I will ask if there is anyone else that is present in this hearing whose name has failed to be called that wishes to offer testimony on the resolution being considered today?

(No response.)

COUNCILWOMAN BROOKS: Hearing none, I want to thank all the panels of witnesses for their participation. We value your opinion. This concludes the public hearing of the Committee. We will now recess this hearing until the call of the Chair. Thank you all very much for your attendance. Have a great day. Happy holidays, everyone.

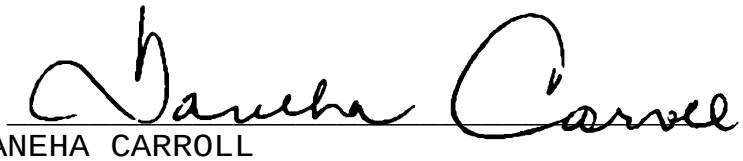
COUNCILWOMAN VAUGHN: Thanks, everybody. Happy holiday.

COUNCILMAN HARRITY: Thank you, everyone. See you, Chairwoman.

(Committee on People with Disabilities and Special Needs concluded at 2:00 p.m.)

C E R T I F I C A T I O N

I, hereby certify that the proceedings and evidence noted are contained fully and accurately in the stenographic notes taken by me in the foregoing matter, and that this is a correct transcript of the same.



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