>> Hello and thank you all for coming.

It's so awesome to see even here. I'm

excited. My name is Sarah. I'm Sarah

Streeval. Just a little bit about me, I

am a mower mother to a daughter who was

born with congenital CMV. Bella was her

name. Bella passed away April 2020.

And after Bella passed we

start pursuing Bella's bill which turned

into Bella's Law. I'm a hands and

voice by my side and I'm a community

chairperson for the national CMV

foundation. And with a few other hats.

But let's get started. This is our why,

this is Bella. Bella was born February

5, 2017. She was three years old when

she passed in April of 2020. Just a

little bit about Bella. She came into

the world in her own way and her own

time and this means that she was

scheduled for a routine C-section but

she was scheduledded the week after she

decided she was going to come. And so

she made her appearance and not shortly

just after she was born, we were sent to

the NICU at Norton Children's

Hospital, which feels the nearest

Children's Hospital for us. They

told me that she was very sick., they

did not know what she had at that point,

we had a completely normal and natural

pregnancy, no complications at all.

After three days at Norton, blood

tests came back confirming she had

congenital CMV. We lad an enlarged

spleen, enlarged liver, we were covered

in D we admirecephaly at birth and also

micro -- I will butcher that but those

were the things we had at birth. Bella

only staid at the NICU for about two

weeks, after that two weeks we were able

to get the virus, the CMV virus that was

in her system under control

enough this it was not bottoming out her

blood platelets and we were sent home on

the antivirals with tons of follow ups.

That next year we figured out that Bella

was full of spirit and spun. She had

an extremely strong personality, mostly

super happy but she absolute let us know

when she was not. You can see in the

photo up here when Bella was finished

with her therapy sessions, she would

fake sleep until she fell asleep. She

was quite successful at this.

You can see in this photo here that she

does not like her hair messed with and

that's what was going on. She was

definitely letting us know. A few other

Clinton Administration things came in

the next two years, we were diagnosed

with seizures within that first year,

seizures however were controlled with

medications in the beginning. After she

turned a year old, somewhere right after

that first birthday S became out of

control. They started increasing

medicationsment we were

hospitalized at six months and the

Children's Hospital trying to get the S

back under control N that time she had a

Vns placed so Ava Gus nerve stimulator

to try to control the seizures. We had

a G tube placed, a the whole GI

system. All these came from the CMV

diagnosis. We were also diagnosed with

cerebral palsy. She was nonverbal and nonmobile and she was

also considered deaf and blind. So now

we're going to talk about how we started

pursuing the changes. Excuse me just a

minute. After Bella passed, we decided

that it was time to start pursuing some

change this is the state of Kentucky so

from my experience and from the

experience earn I knew at that time CMV

was not being screened for, parents did

not know what CMV was, we were

uneducated. We

had no clue what CMV and then it was

very limited what we knew then. So we

wanted to change this, and in April

of last year we became the seventh state

to implement both targeted newborn CMV

testing and CMV education for the

expectant family families, so this was

super importanttous because I wanted

to make sure that families were getting

educated. The CMV testing is not

ideal but we're going to take what we

can get for now and keep working. And

yes Kentucky is one of the many states

that rely on the recommended uniform

screening panel for the standardize

newborn screening. Hopefully at some

point that is also going to include CMV

screening, that is something that's

being worked on a national level so

until then we will saw the

laws on a state level, this is our quote.

Indeed it is the only thing that every

has challenged the world so these

people have been my absolute backbone,

my confidence and my guides through this

whole process. So my first step was to

collect the people who wanted to see

this change. So we created the task

force.

And this was the backbone of it. My

specific job in this task force was to

gather the the families. As the parent

in the task force that was my

responsibility because I'm the one

that's going to have better access to

the families and they're going to

respond better to a parent, is the

consideration. So this is the results

of what I had done. With I we actually

a few more than this, we are up to 50

family this is the state of Kentucky,

seven of those are passed away. The I

think range is anywhere from one to 32

but most of those are under the age of

13 and we have family this is 21 county.

By means this is not all of the kit does

in the state of Kentucky but these are

the ones that I have connection with and

I have contact with and we include them

in our data. You can see is that there

are areas here that we are not well

represented. Those are areas that

either are not seeing the professionals,

either in the north or possibly this the

south. There are some areas to the east

and west and even to the south there

that we think may be going to other

states for help and so we're working to

get better coverage in those a sections of the state. Know your

stakeholders so you have to figure out

who wants change. The families was

number one for me, you also have

your medical professionals, your early

intervention providers and legislators

and we're going to look at -- this is a

few of the people that I have on my team

that was deeply invested in change.

Dr. Shelly molt, an audiologist, we had

an infectious disease professional and

I'm not going to read this all to you

but I'll be glad to send this to anyone

who wants to go over it in more detail.

These are the few of the organization

that backed discuss that really

supported

us, so hands

and voices, deaf blind frontage,

Kentucky counsel of the deaf and

hard-of-hearing, development digitty

council and advocacy for accessible living.

All these people helped guide us as we

went about seeking legislation changes.

This is our road map the changes. We

began with increasing education and

awareness. So a few of the ways is that

we chose to do this is we did create a

website with more information, not only

about Bella and about Bella's bill but

about all the families that we were

representing in the state of Kentucky.

So as I started collecting the families

in the state of Kentucky I began to get

their stories and my job was to go

through and find out what the family

story of CMV was, put that into a one

page document, and then put all of those

on to our website. So each child was

represented in each different

circumstance. We opened several

targeted social media accounts such as

Facebook pages, we opened

Instagram and other social media accounts.

We hosted educational webinars, we

actually hosted two or three of those, I

believe. And educational

webinars were for the families, but

also for the professionals and the

legislators. So everything that we had

done website wise, social media wise or

even educational webinars all of these

we were sharing with our legislators and

and it was super important that we bring

everybody to an understanding. We

utilized many media outlets in the

process.

This is a few of the things we used, so

you can see the brochure that was on the

left over here. I had an awesome friend

that was on our workforce that she is

awesome at graphic design, she designed

all of those things for us, we came one

an awesome logo, Bella's bill for CMV.

We picked some specific photos that went

kind of nationwide. And those specific

ones and used them routinely, we gave

an can explanation on what CMV is,

information about CMV. You can Al see

on the left the

small photos are kids in Kentucky,

that's not all of them but several of

them. The one this the middle is

actually an advertisement that I used.

I used this mostly on immediately but

also in some other agencies, professional

agencies, but I used this on social

media to attract the families that are

from the state of Kentucky. So if your

family has been affected by CMV I got

several calls from parents who

were in the state of Kentucky who were

in never reached by anyone. I had a

family in bowling green who had a adult

child who was an adult age and she never

met a family that had a child with CMV

their entire life so it was pretty

awesome getting to meet people who

hadn't had any exposure to other families.

This is an example of the stories is

that we put together so things the one

about my daughter but we put together

stories for each of our 50 kids that

are in the state. And this is also what

I we used to send to legislators so

at part of my job was first things out

where the families were, who their

legislators

were shiverings mapping out the famil

ies and I was going in and figuring out

who their legislators so when we contacted

them I was like these are the kids

in your district and when we contacted

the families we said this is your

legislator and this is what

you need to send them, this is the

information they need. They need to

know who your child is and how you're

tented and that you're in is their

district. So know your legislators. On

multiple supporters going

into session in person. We went to

Frankfort at least five times. Knowing

ones that are going to be on your side

so we picked out the legislators that

were audiologists and those were our

biggest supporters. The

medical professionals on

the legislative level were not the best

supporters just FYI. Those were more of

a challenge for us to get on board with

but the audiologists were definitely on

board, we had some that were nurses,

those were great supporters so know who

your legislators are, know

what they're going to want you to tell

them, so make sure you have on both sides

-- make sure you have both republicans and

democrats, you have to show them a face.

They have to put a face to this so not

only did we go but we went and took

Bella's wheelchair and her photo so she

was recommended but we also took a power

point of every child in the state of

Kentucky. Give them the number asks

give them a why. So this is a little

more information about Bella's Law, in

when it was enacted and what it provides.

We did have to come to an agreement at

this point, so we are going to -- Bella's

law provides education for the

expectant families. And the targeted

CMV testing for if babies that

failed a hearing test or have other CMV

symptomology, so there are screenings

being done at birth and if they fail

them they are tested for

CMV. Kentucky hands and voices has

helped on the front and back side but I

have been able to partner under harmeds

and voices as a guide by your side so I

am a CMV guide for the CMV family in

Kentucky and I contact those offering

peer support and resources. Here's our

website and a little more information.

Your welcome to take a photo of that or

if you want to leave me our

e-mail I'll be glad to send you to

PowerPoints. I think we have a few

minutes for questions. Any questions?

>> Let me get you for the captioner.

>> What are you hearing are the barriers

to universal screening? Like,

what are they telling you? Is it

expensive? Is it time. Like, what are

they saying --

>> Mostly it's expense, mostly. It's

also getting the medical professionals

on board, not positive of the barriers

but with few of the things we have heard

has just been they don't want to scare

parents. Like, that one kind of blows

me away but they do not want to scare

parents on the front end because they

don't feel like they have enough they

can do about it. Granted there is no

CDC intervention for if expectant parents,

am I correct on that at this time? But

that is something that is -- can be worked

on and is being worked on. So it is

still in those -- what do we call it?

Yeah, we're still in clinical

trials and without the data and without

the information, we're never going to

get I don't mind clinical trials.

>> Rebecca Leverson, pediatric

infectious disease so you're right Sarah,

there is nothing that currently we can

do for a mother who is diagnosed with

congenital CMV during her pregnancy and

we'll go over more in regards to

the biology with that, but with regards

to universal testing is what do we do

with baby who is completely asymptomatic?

There's still an ongoing trial or is

there benefit of six months of twice

daily oral medication that has side

effects with it for a baby who is

completely asymptomatic, and until we

know that millet is to do no harm, so

we're stuck where we need that clinical

trial data o so that we can go ahead

forward to advise you, yes get screenings

every month for the first three years

of life and every six month after that

until you're six and once yearly until

you're 13 if you have asymptomatic

congenital CMV but do I give you

medication, but we have one company that

is working on clinical trial for a

vaccine, and that

may be our goal to vaccinate women prior

to pregnancy or during pregnancy to try

to peremptory CMV infection.

>> Thank you so much.

>> Yes?

>> In some of the research I've done

I've uncovered a letter to -- I've

forgotten to whom it was written and

what state but they put forth several

questions and this one is from last July.

One question is why do women go

universal when 85 percent of the

children remain asymptomatic for a

lifetime? And if you find it what are

you going to do about it? There's no

cure at the moment, so what's the plan?

And also the cost is a concern too.

Nationally the average cost is about $57

a test, where the hospitals have

inlaboratory based

upon volume making I would $12 a test

but when you start talking about screening

for the other genetic

disorders we're talking penny and not

dollars as a cost of all of the tests,

screening and test together.

So basically the letter concluded with

the idea that the rest is not totally

closed to the idea of eventually

including this but it settle the bar

high for answer to questionses

before they'll seriously consider it.

>> Thank you for that.

>> My only question is if we're not

really testing universally how

do we know the numbers and how do we

know that 85 percent remain asymptomatic

if we don't even know the numbers so to

me the greater challenges -- I'm not

saying -- I do hear and understand all

those as well as the concerns but I

think we don't know what we're talking

about, numbers but we're responding as

though we do. If we don't test we have

Ec reality sense of what the

numbers are because most are tested

after the 21 day period which can not

rule out acquired so that's my concern.

>> So I understand all of the concerns

about universal screening for CMV and

the cost and the lack of treatment, but

one thing I often wonder is about is why

don't young women know more about cCMV.

It is preventible with care, with hand

washing and protecting -- not sharing a

spoon with your toddler who is in

daycare, et cetera. We have PSAs for

teen pregnancy and I'm just curious as

to maybe somebody has some insight on

why we don't have more public service

announcements around cCMV for young

women.

>> Just to answer that quick question,

there has been quite a few notices to

OBGYNs that educating pregnancy women

can be cumbersome to an expecting mother

which for those of that have CMV kids

that's not true, education is important

so I want to step on your presentation

but I want to say thank you so much for

if sharing Bella with us, very

appreciative of it.

>> .so I'm from Arizona, we don't have

any CMV testing in Arizona. We have

just started -- we just forward a very

small pilot of universal screening in

the hopes of generating some

more dollars that we can use for a

larger pilot studyN part to answer the

questions that been brought up what's

the prevalence of CMV in Arizona and

nobody knows the answer to that, so

we're basing the decision that are

being made on the medical level and on a

legislative level on numbers that don't

really exist at this point. And so

we're using what other states have done

or what we can pick up from if

everywhere else to try to do that, and

so we are hoping that by generating

a real set of data from real Arizona

mothers, that we'll be able to make some

arguments about it. And we tried to

leave thatch to say we don't know what

the right answer is. Is universal

screening the right answer? How can we

know if we don't know the right numbers?

The second part is as a separate arm of

our chapter of the stop CMV in Arizona

we have started doing some educational

things as well, and they're really going

to be able to show that nobody knows

about CMV so mothers or pediatricians

or members of the general public just

don't know very much about it so I think

that we've started with OBGYNs and

pediatricians and just trying to do a

broader rain of options but I

think the points that are being made are

really salient to everybody on the

ground level.

>> Thank you so much. I agree.

>> I will tell you that of the 50 the

families that are in the state of

Kentucky, there was only I think two of

those who knew anything about CMV, the

one family that knew about CMV was

because the spouse of that mother had

had CMV. And they actually notified

their doctor of this and was told it was

not a concern. And no testing was done.

And this child was detected later on,

not at birth. And that's just with our

numbers.

>> Hey Sarah, thanks for again sharing

Bella's story. I'm in North Carolina.

I'm on audiologist and we do a lot of

work with hospitals and parents and PCPs

and my question is what are you providing

actual hands on literature or fliers or

handouts? Are you using that brochure

to -- have you gone gone out to OBGYNs

and said can you hand this stuff

out? Like, how are you trying to get

that information out to expectant moms?

>> We are still working on that end, we

started with the cabinet and the cabinet

has provided some information, not

enough. I think they have a link on

their website that tells parents

about CMV, so we are planning to -- this

brochure has been handed out but we've

not widespread handed that attelet so

yeah we're still working on improving

that and once with got the law passed

it is manging sure that it is inmented

contradictorily and then make sure that

we can boost up parts of that law.

The first just to get the law in

place.

>> Just our curiosity are you required

to have legal backing to do that? And I

ask that because in North Carolina, our

Eddy program we are able to develop

materials and we give that information

to primary care providers, like are you

able to potentially work with Kentucky's

edit did I program and say can you help

it us get this information out?

>> We have worked with a Eddy program.

That brochure is not being handed out

but they have brochures that

they are handerring out and we are

working with them on referrals and the

state is working on the direct referral

system. However they are serve referring

families to me so I'm able to pass out

my own business cards and they give

those to the family and they refer them

back to me, or I can hook them up with

more resources, is we're working on it.

We're not where we need to be yet.

>> I have the last question, just to

clarify your legal conclusion was really

for the education and testing if there

was a misscreen or a failed screen but

no ask for funding, correct?

>> Correct.

>> Thank you.

>> This was not a budget year for

Kentucky so if we had put a money on

that it would not have passed and we

weighed aromases of whether to get bid

in the books or to wait until it was a

budget year and we decided that it was

best for us to get the law because we

kind of had legislatorses where

we needed them to be and we thought it

was best to run for the law right now

and work on the budget and boosting that

up after the fact.

>> I think that's it on my time. Thank

you guys so much.

>> You know we have a quick turn around

so if you're not staying . . .

...

>> I do some business cards if anyone

wants one or you want the leave me your

e-mail.

>> We have our evaluations in the app.