>> Good afternoon. Welcome everyone.

So excited to spend a little time with

you today to share more about our

organization expecting heft and specific

ways we've been working the meet the

needs of family leaders with engagement

and support. My name is Marianna aria.

And I'm here with my colleague who's

going to introduce herself in a hospital

moment. But we wanted to give you a

brief background on Expecting Health.

So at our core we're a nonprofit

organization that is really centered

around bridging the gaps between

the systems that we all are employed at

and the realities that those of us that

are a part of the medical systems

experience, so we work in a number of

different programs and

two of those center on specific and

strategic ways to engage with families

so we can need their needs where they

are and provide support and encouragement

and engagement in ways that meet

their needs. So today we're going to

share with you more about the

[indiscernible]. And both of those

projects with funded through

the health resources administration so

we do thank our partners around this

work to be done. With that I'm going to

turn it over to Mary.

>> Thank you. My Marianna said I'm

Molly and I am -- I get the privilege of

running the national genetics education

and family support program which we call

The Family Center and before we kind of

go into some of the work that we're

doing we wanted to center you around a

little about how we think of these

terms that far thrown around, family

engagement, family support, family

leadership they tends to get

interdispersed like commingled

together and people mean different

things, so when we think about some of

these things, when we think about family

engagement we think about that as

families that are able to participate as

equal stakeholders in systems and when

we think about family support we think

about the support that families need to

get that access can to have what

they need when they're looking for that.

And family leadership is that piece that

ties it all together, that part of it

where it's that learning

so they can participate in those

systems there that engagement or they

know where to get that support, so we

think of all of these things sort of

independently but mixed together and

it's along a continuum. So support

where families find it I see a lot of

my family leaders that are in here that

have been part of this systems work, and

we know that families find support in a

lot of different places so it's parent

to parent, fight it through information

whether that's on the web, they find it

with professionals and adults with lives

experience and within their communities.

So now that I kind of like I said I set

that stage for you to think about it,

now we'll see how examine

Expecting Health applies

the principles and ideas around the

programming, so like I said

this is I'll talk about The Family

Center. The Family Center is fund bid

the federal government and it's really

to provide that opportunity to to

develop family leaders within the

genetics health care space, and so they fund three different tiers of

that, so they fund the family sister and

they also fund several regional genetics

networks so the Rgns cover all 50

states and a couple of the territories.

And then the national coordinating

center for the regional genetics

networks act as that body that

collects that information so it's

between those three to create a

coordinated system of care in that

genetic space. So The Family Center

really has a couple of different aims.

We're looking to provide culturally

linguist appropriate

education, and how they can incorporate

family leaders within their work. We

train individuals and families to work

within that genetic system and provide

support to individuals and families who

are looking to work within that.

We do this through a couple different

ways, so we have a website that really

is looking to meet families where

they're at around genetics. I have -- I

get the privilege of working with a lot

of people who are passionate about

genetics, and they as soon as they find

us they want to pull up that square and

start talking about, ands and Yes

and we try to take that website and say

that's great and some families want to

learn about that and some

families don't so we try to set the

website up so it's where that need to

know around genetics and if you want to

know more where you can find those

resources. We did a podcast, we brought

together three different family

leaders that were at different points in

their journey and talked about that

family leadership piece and we have some

opportunities for peer learning as well

as webinar asks leadership trainings.

So this is our website so again it's

that home page; again, understanding

genes and genetics, that genetics

journey and we have the family

leadership section, which

contains some of our leadership

trainings that we've done. We set up

up into four different spaces where we

do the individual, the community, around

the system and now I'm missing one

because I didn't the write it down and I

left really early this morning so I

apologize but we have some

online learning modules,

some blogs and videos and stuff like

that, again trying take those topics and

learn from echoism them. So

this is our who's a family leader from

that very basic, sort of is that idea of

what constitutes a family leader, we

have objectives and then again you can

-- it's self paced and it's captioned,

you can go through and it's in Spanish

as well and you go through that module.

Here again was our plug the for our

podcast which we have on YouTube as

well as places where you can get podcasts

from, wherever you listen to those. Or

we have the transcript with them so they

are accessible. So just a couple last

minutes about some of our peer-to-peer

because again, we know different

leaders work and learn in different ways

so we try to support different family

leaders so we do peer-to-peer

opportunities. We have a family center

work group on inclusion which is really

made up of about seven to ten individuals

who are looking at what is inclusion in

the genetic space and how to increase

access to that and what are projects

that they can do so coming up this year

they're going to do some webinars can

trainings. Then we have our

family center community of practice on

diversity equity and inclusion so

offering that opportunity for family

that are looking to discuss an article,

bring it back to what they have in their

realm of influence and how they can do

that. And then for family leaders that

are really actively involved

with their RG N, we have parent leader

office hours to support them around the

work that they're doing within that.

Here's a couple of opportunities for

involvement, so you can stay up-to-date,

again we have, like a lot of people we

have our newsletters, we have our social

media accounts where we tend to push out

our information. If you want to join

our community of practice you can send

men e-mail and I would be happy to send

you a calendar invite, it's pretty

casual. If it doesn't interest you that

month that's fine too. There is my

information and then we have a booth up

in the exhibit hall so if we don't

get to questions -- we're trying to

leave a few minutes for questions but if

we don't Marianna and I will be at the

Expecting Health booth. And now I'm

going to turn it over to Marianna to

talk about our other project around

screening.

>> Thank you Molly. [indiscernible] and

if you missed introduction again my name

is Marianna a ya and I had the

privilege of working on our funded grants

called [indiscernible] education

program. We often refer to this as

newborn screening so if you see things

on social media or print that say

navigate newborn screening that is our

program and really our vision is to

create a landscape where all families

have access to -- have equitable access

to newborn screening information and I

know there are many of you in this room

that can appreciate that perhaps the

first time you learned around newborn

screening was when you sheaf

received a phone call and through this

program and we tried to change the way

information is shared and education is

delivered to families there you had

throughout the process of newborn screening

so we think of newborn screening is not

just something that happens at delivery

but an entire system of stakeholders,

including families. So I won't but

there all of this but I want to point

out that there are foreign aims this

program works to serve and our first is

to second families so we have a number

of differentA.s through the the program

and this program is in its last of five

years, so we've done a number of

different things to create materials to

develop opportunities and through

online learning to provide education to

families so that we're truly meeting

families where they are in that journey

and a large part of our work is centered

around partners and I see many of you in

this room today, partnership looks and

feeled like different things but every

family we engaging with is a partner at

that program and we firmly believe that.

So we have done a number of different

things to build our dissemination

partnership network so we can continue

to share the resources in ways that we

have been engaging with families

throughout the new born screening system.

We have more formal or structured

program for family leadership that we're

giving another presentation tomorrow,

but just to point out again that we have

a number of different

activities that are centered around

family leadership development and train

ing and ways is that we can engage those

leaders into different leadership

opportunities within the newborn screening

system. Maybe that's at their state

lab, a national level and again that

looks and feels different for

everyone.

And also all of the evaluateth activities

that I with think of through this

program and I would say throughout

Expecting Health are focused on meeting

families where they are and reaching

communities that maybe haven't been

reached before so we've

been able to work with communitys or

families from the virgin islands and

we've been doing work with Mennonite

families as well. So really trying to

engage in different way and today and

this is really exciting to share throw

it's through all of these different

activities which I haven't

talked specifically about them we've

within able to reach over 3 million

families so we're spieded about that.

Again through online learning, through

education, through discussion groups

we've been able to train over 3,000

families and we've done that in

partnership with 64 and growing

individuals as well as partnership

organizations. And at a date we have

ten family leaders who completed

our first training program which

completed last August can we currently

have another 12 family leaders who are

going through a training program right

now. So when you think about meeting

families and throughout the newborn

screening system and really thinking

about what does it look like to meet

familyings where they are we think about

that in three big categories. This is

also relatable to how a family may grow

in their leadership journey throughout

this experience and so the first way we

thought about ways to engage

families is to built awareness, so first

build more knowledge and awareness that

newborn screening happens, why is I

important and even if it isn't something

that is currently a priority in an

individual family's life it has affected

them or may affect them in a future so

through a number of different specific

partnership initiatives we've been able

to introduce prenatal education and

again medically underserved hard to

reach community. We have done a number

or have had a number of -- rather we've

been able to have outreach and have

success through social media complain

campaign. Once we raise aareaness and

generate interest we offer a variety of

different education opportunities and

one of the first things this program

developed was an online training module

that many of you may have seen, it's

available to any professional and it

goes through a five part introduction

and series, not just what is a newborn

screening but what are all of the parts

to newborn screening, how is the federal

role in determining which conditions

are added to a panel, what does it look

like at the state involvement and what

are the different parts of the system

that may be happening within your

state so that online curriculum is

online for any family to take and we

have it with live speaking, again kind

of understanding can

recognizing that all families have

different needs so we've tried to create

an abundance of resources so there is

something for everyone that we can find.

And lastly as I've mentioned our family

leadership program which we lovingly

call our navigate newborn

screening am because door program and we

have some of our ambassadors here with

us and we'll be sharing more detail

about that program tomorrow. So there's

a little bit of overlap here we focus on

a number of key strategies when we

think about how do we best engage and

work with different families and this

was the strategies is that helped us

build our prenatal education program.

So first and foremost it's ebb trimly

important us that we spelled a

significant amount of time anytime we're

introducing a new engagements to

understand the cultural perspectives so

working through our partner that we have,

asking a lot of questions to understand

what are the means within the different

communities that we're working

with and what do we have available that

can help us meet those

needs and what we've seen throughout theA.s

of this program is we've had a lot more

success when we're sharing the

information can engaging through trusted

resources. Times that's a midwife,

sometimes that's through social media

because that is where families go to

get information, so again asking the

questions to first understand

what the needs are and then identifying

those trusted resources and going

to those trusted resources to

send that information. In particular

when we're working to introduce prenatal

education throughout our community

experiences a key to that success is

understanding what the workflow already

was and what I mean by that is is if

you're going to introduce an

educational initiative during pregnancy

that can feel like a lot so thinking

about what are the other I points of

education that are happening in that

process and working into that point that

already exists and working with

the health care providers, really

thinking about what's already in place

and going there to ask the questions and

work with those groups and

again a number of different communities.

Then the other two big things are to be

able the think about is it practical

materials. I've mentioned social media

a couple times, that has been a

successful tool for us to engage. It's

also been a successful tool for us to

reach family asks share information but

that's not the only thing. We worked

with an Amish population so we had to be

able to build the tools and materials so

we were able to do similar things with

paper materials through the mid wives

and in those communities and sill still

have success and last but not he's all

of this is founded on trust and it takes

time to build is that trust. So in

these last three slides I'm going to

quickly show you the tools and resources

and thinking about engaging families

as individuals and in engaging families

as a community and at a national level,

so if you are interested and Molly

mentioned we have a booth but please

feel free to scan this QR code that will

take you to an online resource county it

I includes our educational videos the

online modules the prenatal education

book. And please feel free to share

this with other friends, family,

community members, clinics that you're

working in. We do want this to be shared

so please feel free to pass it along.

Edie want to talk about engaging families

as a community and how we did that

specifically through the social media

campaign, as I I mentioned we did that

over a six month period and we had a

series of very specific educationally

focused ads that provided information

specific statistics and education around

newborn screening and we were able to

target those ads to roughly 6 million

women who all expressed an

interest in pregnancy so they were

either pregnant or had already had a

child or had an interest in pregnancy so

there Facebook and Instagram we were

able to reach a significant number of

the available population, so around

2.9 million individuals through this

Facebook campaign were reached and we

had pretty successful engagement

and earned about what it takes to

measure social media engagement. So I

see some of you nodding and that was new

for me and it was definitely a good

learning experience but the bottom line is we had great

engagement through social media. Some

other ways that we have engaged

communities as Molly mentioned in their

paragraph we have various different

opportunities to meet families as a

discussion group can we schedule that

throughout the year, we have a number of

communities of practice where families

and organizational partners come

together to talk about issues with the

newborn screening system and more

importantly collaborate to

problem solve and find solutions that

work. We have work groups and

throughout all these different

opportunities family are

engaged in that entire process. And

last but not least we're excited about a

family leadership program that we've

been able to 2021 and facilitate where

we train single family leaders through

about a ten month training program 789

this map is showing you in the teal the

color the states where we had

family leaders go through the program

last last year and you can see from

the list of conditions we have tried to

include families from all aspects of

new born screening, include blood

spot hearing and heart screening. We

have a variety of diversity and

locations and from

sense of the word divorcety so. Following

the completion of the program we haved

a number of opportunities where family

leaders have been able the come to

things like this where they have been

able to participate in the steering

communities so we help them to connect

with other culpabilities withen the

newborn screening system so that they

can continue to take their leadership

journey on. So to wrap up and we'll

have a few minutes for questions,

what have we learned from this? We've

learned southpaw the three things that

come to the top are engaging family

truly requires multiple strategies so

we think of it as a one way thing and to

truly meet families where they are it

takes a lot of different

affidavits, a lot of different resources

to engage and meet families where they

are, and partnerships are critical.

They're critical to establishing truster,

they're critical to ensuring the the

resources get shared and the most

important resource is to partner with

families to be a part of that entire

process from start to finish. So with

that we thank you so much for allowing

us to opportunity to share about what

we're doing at Expecting Health and this

is my contact information, and then of

course we'll available after and at our

booth. So thank you

very much.

>> I was wondering do you have any

resources --.so I was just wondering if

we have any resources in other languages

or just only in English.

>> I can talk about some of the resources

that were developedded with The Family

Center work, so our website is in

multiple languages and we actually -- I

don't know what the I.T. technical term

is but it will translate but we

wanted to make sure that that was

accurate so we had the widget translated

and run it through some different

communities that spoke

different handles and that has over 80

languages and all the resources on The

Family Center website are also in

Spanish so the online learning modules

and we were conscious about other

languages so if we recorded a

family story and their first language

was Spanish we kept it in Spanish and

included English captioning underneath

it.

>> .

>> Would you explain what support you

families after diagnosis? Do you hand

them off throw the spin

organization?

>> I can talk about it globally so again

so if you think about it both of our

programs -- so we talked about

organizationally but also both of our

programs are federally funded but our

aims are not at that individual level

per se but having said is that again, if

a family would -- is we're trying to

work through to develop the systems so

there are those connections so again I

work this a little bit different space

than Marianna but we would -- if a

family would contact us directly we

would do a handoff. I don't know if

you want to mention anything about

newborn screening or if there was

anything different.

>> Obviously, it's different every state

and I'm in Ohio and our state is not one

of the lucky states but my curiosity is

do you have any partnership with hands

and voices or guide by your side

program? Or what does that like

.

>> Great question and I'm happy to

answer that yes we do have a partnership

with hands and voices. I've

attended the coordinator calls so

all of our partners -- we work

with our partners in different ways so

they have opportunities to participate

but within that we also have more direct

partnerships where we may do more

[indiscernible] with hands and voices we

actually wrote an article that went out

in [indiscernible] and had QR codes with

our resources so there's creative ways

that we work individually with our

partners and we're always open to doing

more of that so if you feel like

something is missing come chat with me

and I'm happy to do more.

>> I think that's our time, so again

thank you very much for attending. We

appreciate it.

>> Thank you everyone and I'll remind

you that surveys are on the app this

year. It's green.