



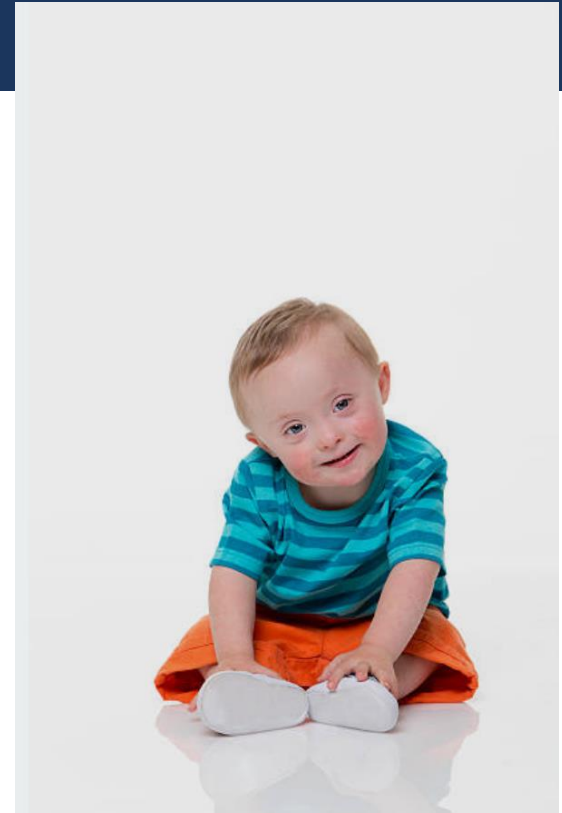
An Introduction to the Tennessee Birth Defects Surveillance System and How You Can Help

Tennessee Health Disparities Task Force Meeting

September 28, 2023

Overview

- Who we are and what we do
- Birth defects in Tennessee
- Health promotion / prevention
- High risk behaviors
- PRAMS data
- Community resources
- What you can do to help
- Contact info



TNBDSS - Who We Are

- Tennessee Birth Defects Surveillance System (TNBDSS)
 - Has been around for over 20 years
 - Created out of a state law that requires the monitoring of birth defects among Tennessee residents
- Why is a Birth Defects Registry Necessary?
 - Early recognition of (and response to) birth defects often promotes early intervention and treatment, which may decrease further complications and disability
 - A birth defects surveillance and information system is essential for the development of programs and policies that can reduce birth defects and infant mortality

TNBDSS Team

Kate Lolley
Program Director



Penny Stepp
Administrative Support Assistant 3



Jeni Waldrop
Public Health RN Consultant 2



Erin Hodson
Epidemiologist 2



Find us at TDH:

Family Health and Wellness > Children and Youth with Special Healthcare Needs

TNBDSS – What We Do

- Monitor/track 47 total birth defects
- Perform enhanced surveillance on 26 specific birth defects, in partnership with the CDC
 - We look at hospital discharge data, diagnosis code reports, birth and death certificate data, other TDH programs, and several other sources to find these cases
 - We perform medical record reviews to confirm birth defects info
- Improve data quality
- Provide annual data information to the public, the CDC, and other partners
- Identify at-risk groups in our state
- Develop and distribute health promotion materials for reproductive life planning, healthy pregnancy, and reducing the risk for birth defects
- Ensure families are connected with support services

Birth Defects in Tennessee



What is a birth defect?

- Birth defects (also known as congenital anomalies) are changes that can affect almost any part of the body and alter how the body looks and/or functions.
- Birth defects are identified before birth, at birth, or after birth.
- Not all birth defects are the same; some are very mild while others are severe.
- Life expectancy may vary depending on the severity of the birth defect and affected body part(s).

Birth Defects in Tennessee

Babies in Tennessee experience higher rates of many birth defects compared to national rates.



**Birth defects affect
1 in every 41 babies
born in Tennessee
each year.**

Birth Defects in Tennessee

Birth defects are the **leading cause** of infant deaths both state and nationwide.

Birth defects cause about 1 in 5 infant deaths in Tennessee.



Birth Defects in Tennessee

Some of the more common birth defects in Tennessee include:



HEART
DEFECTS



DOWN
SYNDROME



CLEFT
LIP &
PALATE



CLUBFOOT



GENITO -
URINARY
DEFECTS

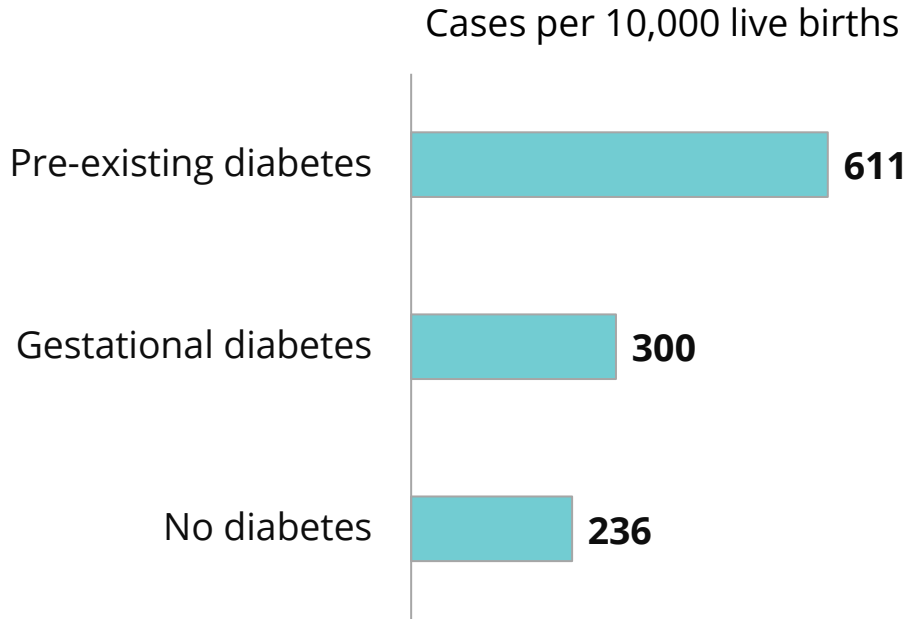
Health Promotion and Prevention

TIPS FOR A HEALTHY PREGNANCY

- Talk to your healthcare professional about reproductive life planning
- Plan and space pregnancies at least 18 months apart
- See your healthcare professional regularly and early in pregnancy
- Discuss any medication use with your healthcare professional (prescription, over the counter, and supplements)
 - Standard recommended Folic Acid dose for most pregnancies is 400mcg at least one month prior to pregnancy
 - Discuss any additional Folic Acid needs (e.g. higher doses and/or starting earlier)
- Discuss family history of medical conditions with your partner and your healthcare professional
- Prevent and/or manage chronic health conditions, such as diabetes and hypertension (both men and women)
- Strive to reach and maintain a healthy weight*
- Be physically active every day
- Remain current with vaccinations, including flu, Tdap, and COVID-19
- Avoid infections and seek medical care for any suspected illness, including sexually transmitted infections (such as syphilis, gonorrhea, chlamydia, herpes, and HIV)
- Avoid harmful substances, such as tobacco, alcohol and drugs (opioids, marijuana, cocaine, methamphetamines, and other "street" drugs)
 - Seek cessation support for pre-existing addiction and/or substance use disorders
 - Be aware/avoid potentially harmful exposures at work and home
- Report any concerning symptoms to your healthcare provider ASAP (including fever, swelling, headaches, heartburn, etc.)
- Find tips to cope with stress and changing emotions and learn the signs of depression & anxiety (National Maternal Mental Health Hotline available 24/7 by calling 1-833-943-5746)
- Partners should also seek mental health support, when needed, both during pregnancy and postpartum (Tennessee Statewide Crisis Line available 24/7 by calling 1-855-274-7471)



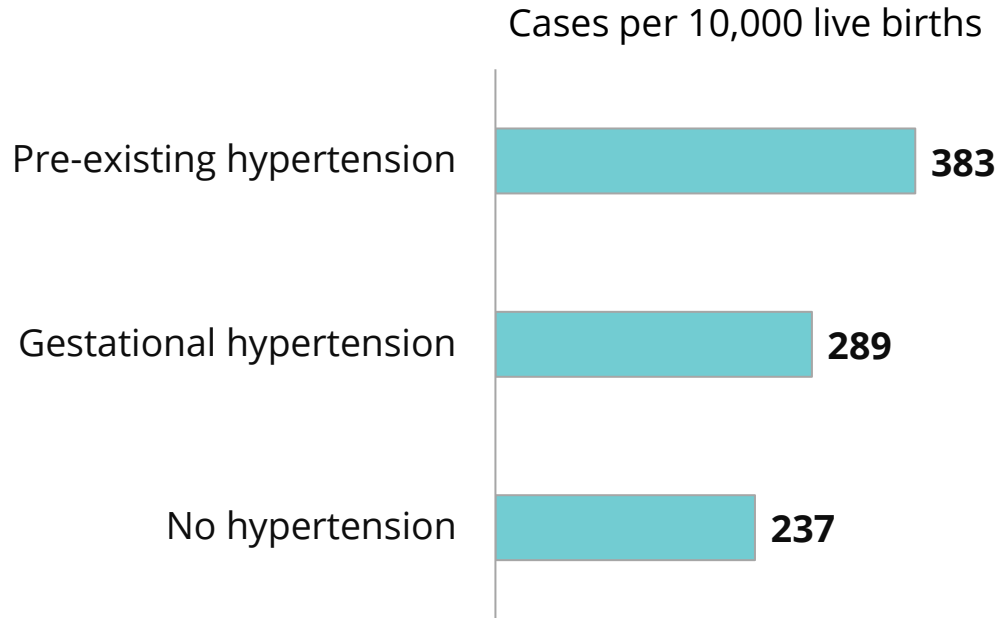
Risk Factors: Diabetes



Women with pre-pregnancy diabetes were **nearly 3 times as likely** to have a baby with a birth defect compared to women without diabetes.

Women with gestational diabetes were **1.3 times as likely**.

Risk Factors: Hypertension (High Blood Pressure)

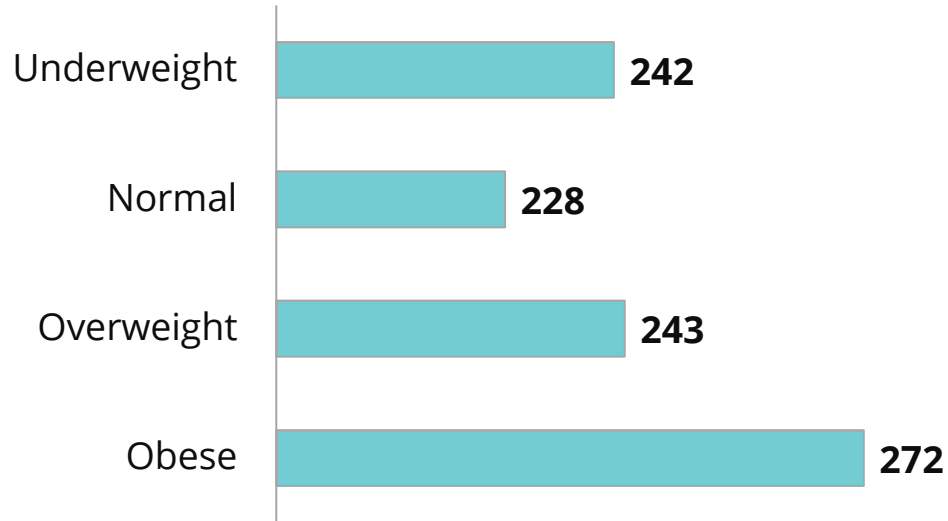


Women with pre-pregnancy hypertension were **1.6 times as likely** to have a baby with a birth defect compared to women without hypertension.

Women with gestational hypertension were **1.2 times as likely**.

Risk Factors: BMI

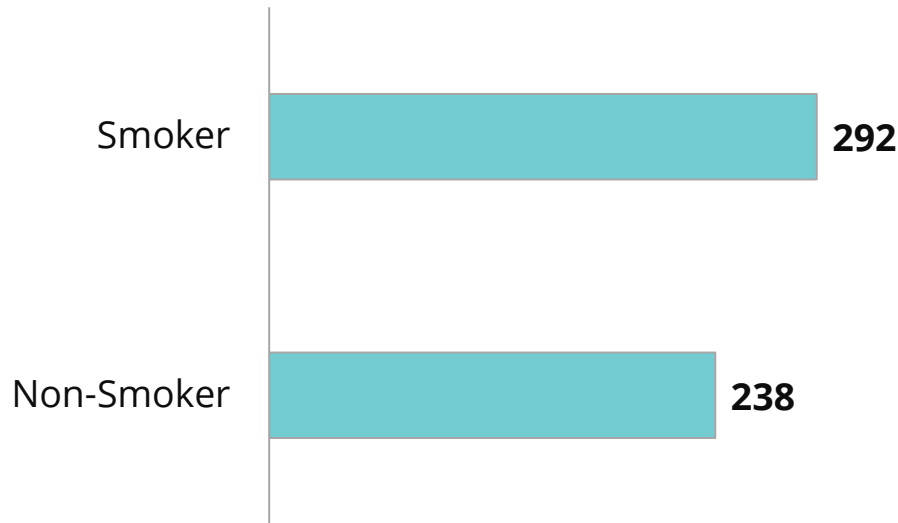
Cases per 10,000 live births



Women with a **normal** pre-pregnancy BMI were **least likely** to have a baby with a birth defect

Risk Factors: Smoking during pregnancy

Cases per 10,000 live births



Women who **smoked** during pregnancy were more likely to have a baby with a birth defect.

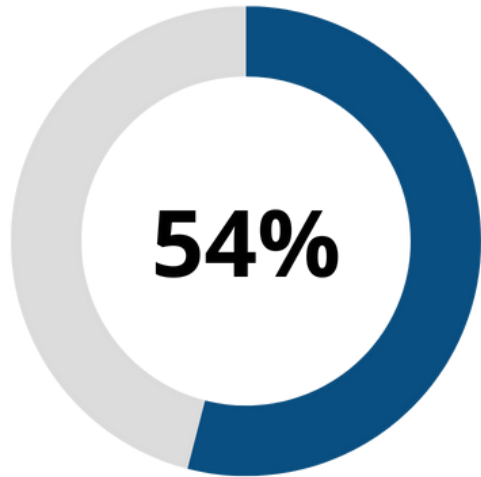
PRAMS Information

PRAMS, the Pregnancy Risk Assessment Monitoring System, is a surveillance project of the CDC

PRAMS is an annual survey that collects population-based data on maternal attitudes and self-reported experiences before, during, and shortly after pregnancy

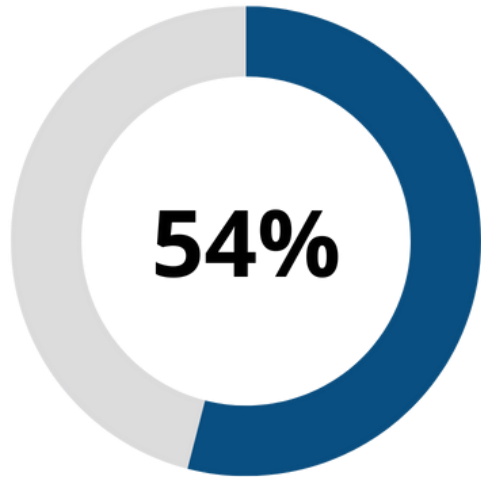


Pregnancy Intention Overall



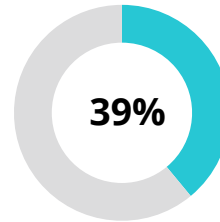
Percentage of Tennessee women who reported that they were NOT trying to get pregnant

Pregnancy Intention Overall

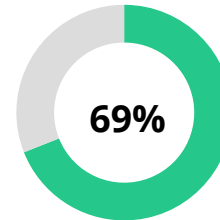


All Women

Insurance Status

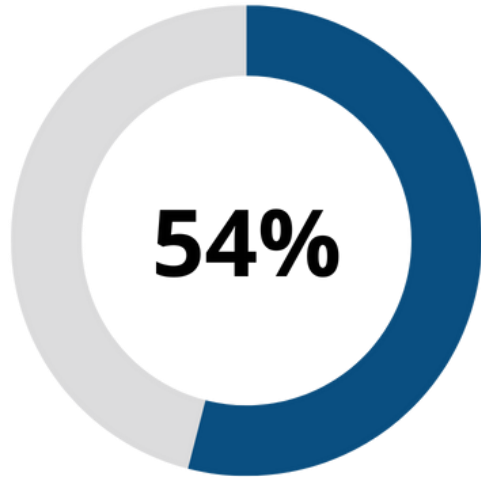


Private insurance

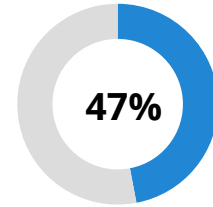


Medicaid

Pregnancy Intention Overall

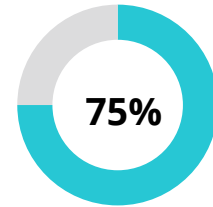


All Women

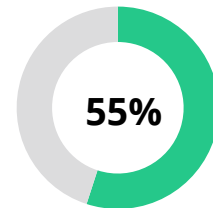


Race/Ethnicity

● Non-Hispanic White

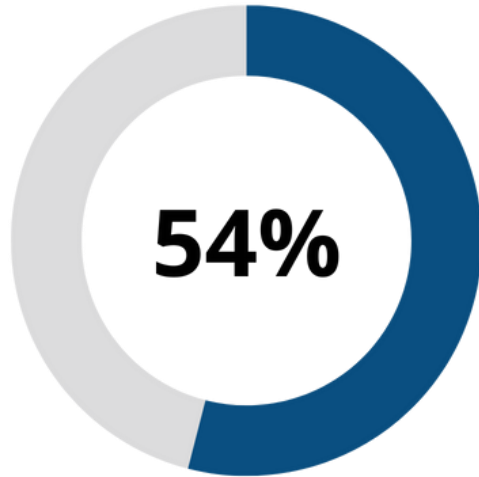


● Non-Hispanic Black

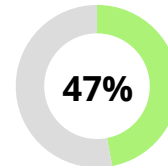
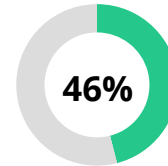
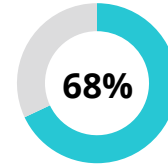
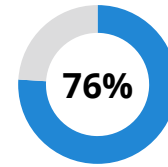


● Hispanic

Pregnancy Intention Overall



All Women



Maternal Age

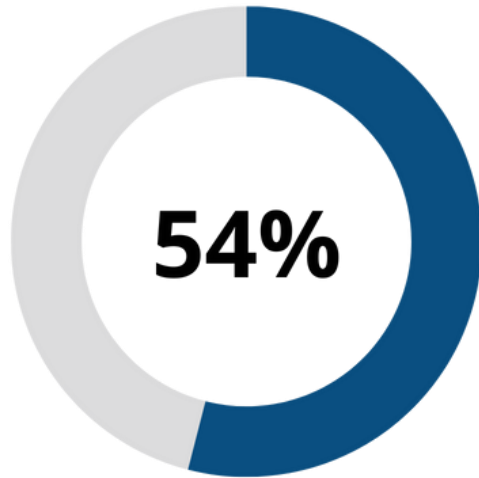
----- ● <20

----- ● 20-24

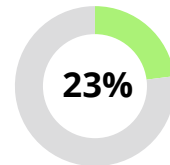
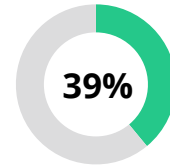
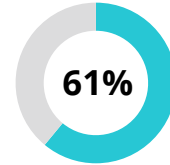
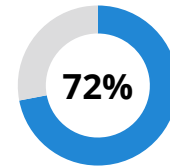
----- ● 25-34

----- ● 35+

Pregnancy Intention Overall



All Women



Income Level

0-100%

101-184%

185-350%

>350%

Why is reproductive life planning important?

Trying to get pregnant	Protective/Risk Factors	Not trying to get pregnant
65%	Took folic acid vitamin before pregnancy	26%
92%	Started prenatal care early	82%
47%	Exercised regularly before pregnancy	35%
12%	Smoked during three months before pregnancy	27%
5%	Smoked during last three months of pregnancy	15%
2%	Diabetes before pregnancy	3%
5%	Hypertension before pregnancy	8%

Partner Referrals / Community Resources

Community Health Access and Navigation in Tennessee (CHANT)

Provides care coordination and assistance in navigating the health and social service needs of qualifying families and individuals for various programs

Children's Special Services (CSS)

Consists of two components: care coordination and reimbursement of medical services or certain non-medical services as a payor of last resort

Tennessee Early Intervention System

Provides services to children from birth until age three who have disabilities or other developmental delays; critically important to supporting young children and their families to reach their optimal development

Family Voices of Tennessee

A program of the TN Disability Coalition; families provide emotional and educational support to other families of children with special health-care needs, chronic illnesses or disabilities; assists in navigating the healthcare system

Partner Referrals / Community Resources



Presumptive Eligibility

A woman with long dark hair, wearing a white t-shirt, is holding a smartphone in her right hand and gesturing with her left hand. She is smiling. The background is yellow with a sunburst graphic and the text "Eliminate the Wait." in a cursive font. Below that, it says "Be seen. Feel heard." in a bold font. At the bottom, it says "Family Planning AVAILABLE VIA TELEHEALTH" in a mix of cursive and bold fonts. There is also a small logo for "TN Department of Health" and a line of text: "Visit familyplanningtn.com or call 1-833-690-0223 to learn more or schedule an appointment."/>

Eliminate the Wait.

Be seen. Feel heard.

Family Planning
AVAILABLE VIA TELEHEALTH

Visit familyplanningtn.com or call 1-833-690-0223 to learn more or schedule an appointment.

TN Department of Health

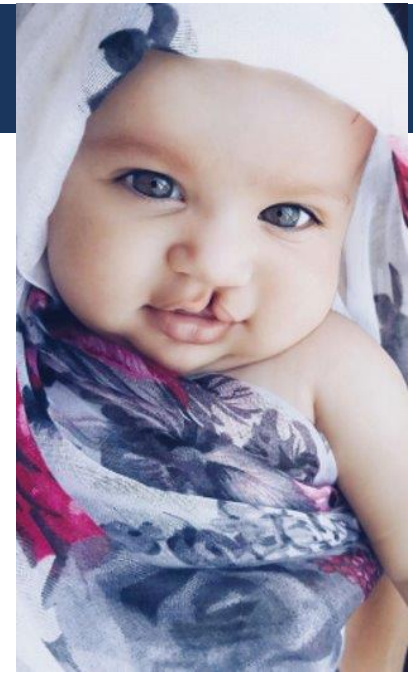
Family Planning



WIC / SNAP Benefits

How You Can Help

- Reproductive life / family planning
- Healthy pregnancy behaviors
- Encourage early prenatal care
- Learn more
 - TNBDSS website
 - Public-facing dashboard – COMING SOON!
- Make REFERRALS to services discussed here today



How You Can Help

TN Division of
TennCare



CHANT
Community Health Access
Navigation in TN



CHANT
Programa de orientación para el acceso a
servicios de salud en la comunidad de TN



FAMILY VOICES
of Tennessee

CONNECT ♥ TRAIN ♥ LEAD

WWW.FAMILYVOICESTN.ORG

TN Department of
Health

TN Department of
Health

Birth Defects Are More Common Than You Think

Every 4.5 minutes, a baby is born with a birth defect in the United States.



You are not alone.

There are many resources and support services available for families and children with birth defects.

Talk to your child's Primary Care Provider.

Your child's doctor is the first place to start in finding support for you and your child.



It's okay to ask for help.

Finding support can be beneficial for you, your child, and your family.



Self-care is important.

Caring for a child with special needs can be exhausting. Be sure to take care of yourself, too!



What resources are available?

Support programs are available for families affected by a birth defect diagnosis. Some of these include: *Tennessee Early Intervention System (TEIS), Family Voices of TN, CHANT, and Children's Special Services (CSS).*



See reverse side for more details on these programs.

LEARN HOW YOU CAN GET INVOLVED TODAY!

TN Department of
Health



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SUPPORT FOR CHILDREN & FAMILIES

REFERRAL CHEAT SHEET

The following resources are available for families caring for children with birth defects. Diagnostic and financial eligibility criteria may be required to participate in these programs.

Please refer to the other side for more information on each program.

TEIS (TN EARLY INTERVENTION SERVICES)

- Online referrals: <https://www.tn.gov/didd/teis>
- Referral phone number: (800) 852-7157
 - Diagnostic list and prematurity criteria: <https://www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis/eligibility-information.html>



CHANT (COMMUNITY HEALTH ACCESS AND NAVIGATION IN TENNESSEE)

- Online referrals: <https://www.tn.gov/chantreferral>
- Program phone number: (615) 532-8192



CSS (CHILDREN'S SPECIAL SERVICES)

- Referrals can be made through CHANT
- Program phone number: (615) 741-7353
 - For more information: <https://www.tn.gov/health/CSSInfo>



FAMILY VOICES OF TENNESSEE

- Online referrals: <https://familyvoicestn.org/get-connected/>
- Program phone number: (615) 383-9442
- Email: familyvoices@tndisability.org



EARLY INTERVENTION IS KEY...

If your practice is unable to submit referrals for your eligible patients, contact the TN Department of Health for assistance. Referrals can be made (with parent/guardian consent) by the TDH directly.

For any additional questions or assistance, please contact the TDH: birth.defects@tn.gov

TN Department of
Health



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How You Can He



Los Defectos Congénitos Son Más Comunes de lo Que se Piensa

Cada 4.5 minutos nace un bebé con un defecto congénito en los Estados Unidos.



Usted no está solo.

Hay muchos recursos y servicios de apoyo disponibles para familias y niños con defectos congénitos.

Hable con el proveedor de atención primaria de su hijo.

El médico/personal de enfermería de su hijo son las primeras personas a las que puede acudir para encontrar apoyo para usted y su hijo.



Está bien pedir ayuda.

Encontrar apoyo puede ser beneficioso para usted, su hijo y su familia.

El cuidado personal es importante.

Puede ser agotador cuidar a un niño con necesidades especiales. ¡No olvide cuidarse usted también!



¿Qué recursos están disponibles?

El Estado de Tennessee ofrece diversos programas para las familias afectadas por el diagnóstico de un defecto congénito. Algunos de los programas se enumeran al otro lado de este volante.

Consulte al dorso para obtener más información sobre cada programa.

¡Aprenda cómo puede participar hoy!

APOYO PARA NIÑOS Y FAMILIAS

HOJA INFORMATIVA PARA REFERENCIAS

Los siguientes recursos están disponibles para familias que cuidan niños con defectos congénitos. Es posible que se requieran criterios de elegibilidad financiera y de diagnóstico para participar en estos programas. Revise abajo para más información para obtener más información sobre cada programa.

TEIS (SERVICIOS DE INTERVENCIÓN TEMPRANA DE TENNESSEE)

- Derivaciones en línea: <https://www.tn.gov/didd/teis>
- Número de teléfono para referencias: (800) 852-7157
- Lista de diagnósticos y criterios de prematuridad: <https://www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis/eligibility-information.html>



CHANT (ACCESO Y EXPLORACIÓN DE LA SALUD COMUNITARIA EN TENNESSEE)

- Derivaciones en línea: <https://www.tn.gov/chantreferral>
- Número de teléfono del programa: (615) 532-8192



CSS (SERVICIOS ESPECIALES PARA NIÑOS)

- Las referencias se pueden realizar a través de CHANT
- Número de teléfono del programa: (615) 741-7353
- Para obtener más información: <https://www.tn.gov/cssreferral>



VOCES FAMILIARES DE TENNESSEE

- Derivaciones en línea: <https://familyvoices.tn.org/get-connected/>
- Número de teléfono del programa: (615) 383-9442
- Correo electrónico: familyvoices@tndisability.org



LA INTERVENCIÓN TEMPRANA ES FUNDAMENTAL...

Si su consultorio no puede enviar referencias para sus pacientes elegibles, comuníquese con el Departamento de Salud de Tennessee para obtener ayuda. Este departamento puede realizar las referencias directamente (con el consentimiento de los padres/tutores). Si tiene alguna otra pregunta o necesita más ayuda, comuníquese con el Departamento de Salud de Tennessee: birth.defects@tn.gov

How You Can Help - Join our Advisory Committee

We're always needing new representatives that include:

OB/GYN

Pediatrics

Genetics

Epidemiology

Biostatistics

Hospital

State Agency

Parents/Families

Members of

Administration

Service Providers

of Children with
Birth Defects

the General
Public

How long is the commitment?

1-3 years *(based on your preference)*

Contact us to learn more!

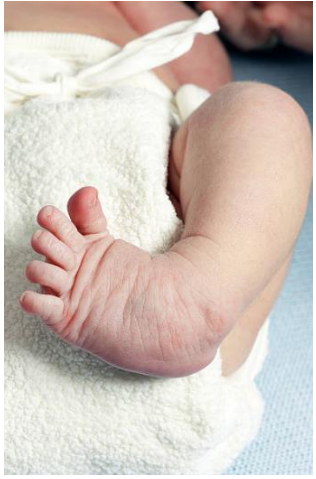
Contact Us

- Kate Lolley – Katherine.Lolley@tn.gov
- Erin Hodson – Erin.Hodson@tn.gov
- Jeni Waldrop – Jennifer.Waldrop@tn.gov



<https://www.tn.gov/health/BirthDefectsInfo>

DISCLAIMER: data and graphs seen in today's presentation will be available in our 2023 Annual Report, which will be published on our website in the upcoming months.



Thank You!