

# ***Infants with Congenital Zika Virus Infection and their Families***

*A Webinar from the Departments of Health and Human Services and Education  
and AUCD's Early Intervention and Early Childhood Special Interest Group*

*Presented by*  
Sallie Porter and Nancy Mimm

February 21, 2017

# Webinar Overview

- Introductions
- Presentation
- Q & A after presentation
  - You can also submit any questions throughout the webinar via the ‘Chat’ box below the slides.
  - The moderator will read the questions after the presentations.
- Survey
  - Please complete our short survey to give us feedback for the next webinar!

# Sallie Porter DNP PhD APN

Assistant Professor

Division of Advanced Nursing Practice

Rutgers University School of Nursing

Newark, New Jersey

Nursing Discipline Coordinator

NJ LEND

The Boggs Center

Robert Wood Johnson Medical School

New Brunswick, New Jersey

Board Certified - Pediatric Nurse Practitioner

Board Certified – Pediatric Nurse

Fellow, National Association of Pediatric Nurse Practitioners



# Nancy Mimm MSN APHN-BC RN-BC

Program Manager

Division of Family Health Services

Reproductive and Perinatal Health Services

New Jersey Department of Health

Trenton, New Jersey

Doctor of Nursing Practice candidate

Rutgers University School of Nursing

Newark, New Jersey



# Objectives

1. Understand foundational Zika virus infection information.
2. Identify case numbers and sources for finding updated information about infants with congenital Zika virus infection.
3. Review current information on clinical findings in infants with congenital Zika Virus infection.
4. Discuss evolving clinical, policy and research implications for early childhood professionals serving infants with congenital Zika virus infection and their families.
5. Identify resources that may assist families with infants exposed to Zika virus infection.

# Introduction

- Zika is spread mostly by the bite of an infected *Aedes* species mosquito.
- Zika is spread by sexual contact.
- Zika can be passed from a pregnant woman to her fetus.
- Zika infection during pregnancy can cause certain birth defects.

# Introduction

- There is no vaccine or medicine for Zika.
- Local mosquito-borne Zika virus transmission has been reported in the continental United States – Florida and Texas.
- In most cases, Zika virus causes only mild illness with most people having no symptoms at all.

# Introduction

- Danger to women who are pregnant or are trying to become pregnant is much greater.
- Zika virus disease and Zika virus congenital infection are nationally notifiable conditions.
- The impact Zika virus can have on fetal/infant health and development is concerning.
- For infants with congenital Zika virus infection and their families, the impact goes beyond microcephaly.

# Introduction

- Wide-spread outbreak in US is unlikely.
- Travel-associated cases will continue.
- Infections will rise again during the summer.

Moreno-Madrinan & Turell, 2017

# World Health Organization

- **February 1, 2016** Ongoing Zika virus infection outbreak is a “Public Health Emergency of International Concern.”
- **November 18, 2016** Zika virus infection outbreak is no longer a global emergency, but it should be viewed as an on-going threat.
- **February 2, 2017** Zika Situation Report

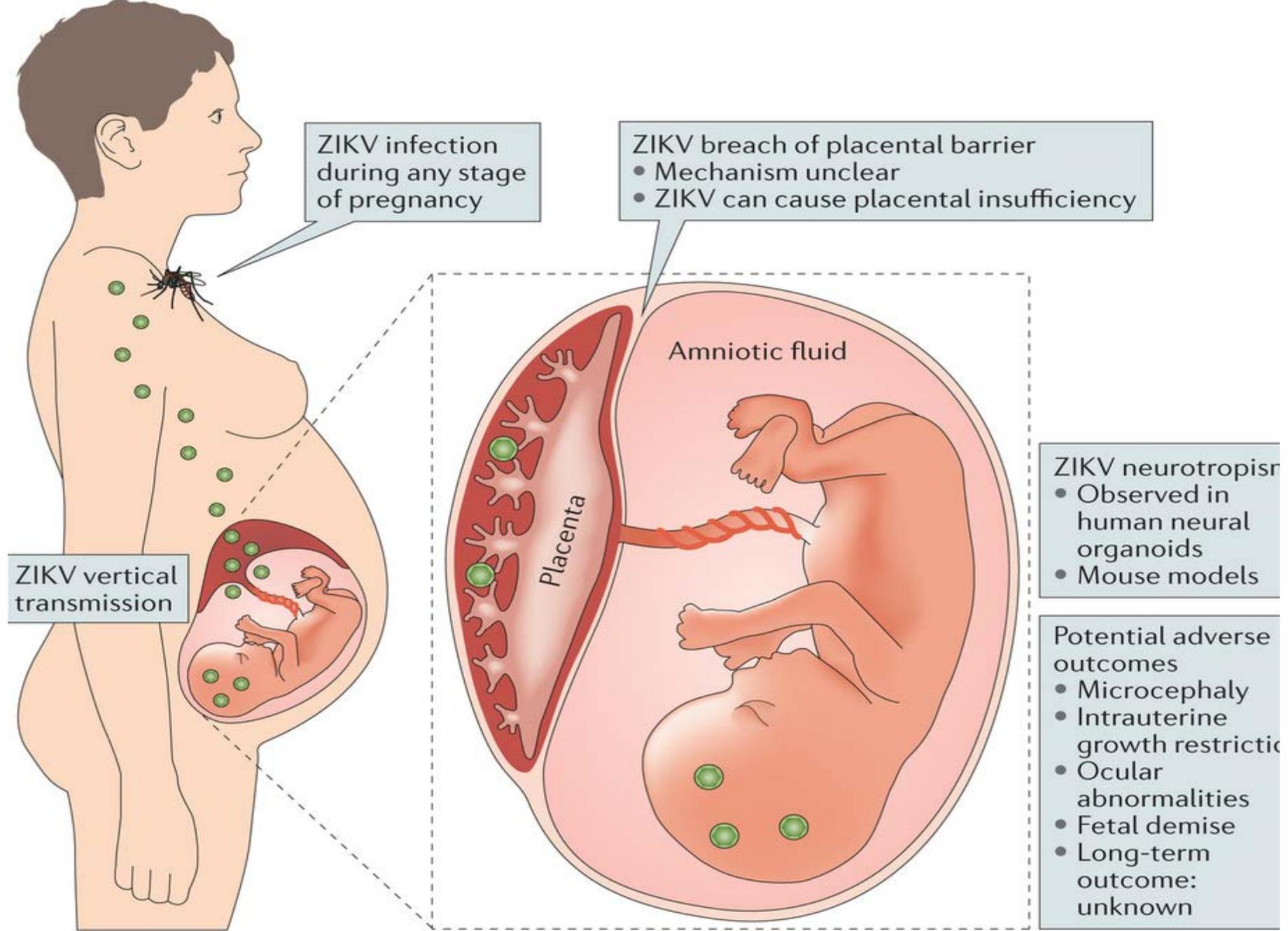
# Centers for Disease Control and Prevention

- Zika virus is “a startlingly complex infection.”
- Continue to warn pregnant women about the risks of Zika and the need to protect themselves, avoiding travel to places where the virus is active.
- Scientists need to continue ongoing studies on the long-term effects of Zika exposure.
- Better diagnostics are needed.
- More effective pesticides and other mosquito control methods are needed.



# Travel-Associated v. Local Transmission CDC, 2017

- Travel-associated cases reported: 5,001
- Laboratory acquired cases reported: 1
- Sexually transmitted: 41
  
- In the United States, locally acquired mosquito-borne cases reported: 220
  - Florida 214
  - Texas 6
  
- Currently, New Jersey has travel associated cases only 175 as of February 8, 2017



# Zika Virus Transmission in Infants

<https://www.cdc.gov/zika/hc-providers/infants-children/zika-transmission-infants.html>

- **How is Zika virus transmitted congenitally and perinatally?**
- Zika virus is transmitted to humans primarily through the bite of an infected *Aedes* species mosquito. *Aedes* mosquitoes are aggressive daytime biters and feed both indoors and outdoors. They can also bite at night. Zika virus can be transmitted from a pregnant mother to her fetus during pregnancy (congenital transmission) or around the time of birth (perinatal transmission). We do not know how often perinatal Zika transmission occurs. Additionally, spread of the virus through sexual contact and blood transfusion has been reported. Organ or tissue transplantation, and certain fertility treatments pose theoretical risks for Zika virus transmission.
- **What is the difference between congenital and perinatal transmission of Zika virus?**
- Congenital or intrauterine transmission of Zika virus occurs when a woman is infected with Zika virus during her pregnancy, but before delivery, and the virus passes to the fetus. Perinatal transmission of Zika virus occurs when a woman is infected with the Zika virus within approximately 2 weeks of delivery, and the virus passes to the infant at or around the time of delivery. When an infant acquires Zika virus infection prenatally, the infant may develop symptoms such as maculopapular rash, conjunctivitis, arthralgia, and fever.
- **If a mother had Zika virus infection during pregnancy or currently has Zika virus infection, should she breastfeed her infant?**
- Zika virus has been identified in breast milk, but infant Zika virus infection associated with breastfeeding has not been reported. Current evidence suggests that the benefits of breastfeeding outweigh the theoretical risk of Zika virus infection transmission through breast milk. CDC encourages mothers with Zika virus infection and mothers living in areas with ongoing Zika virus transmission to breastfeed their infants.

# Pregnant Women with Any Laboratory Evidence of Possible Zika Virus Infection in the United States and Territories

- United States and District of Columbia (1,455)\*
- US Territories and Puerto Rico (3,156)

\*Includes aggregated data reported to the US Zika Pregnancy Registry as of February 7, 2017

CDC, February 7, 2017 <https://www.cdc.gov/zika/geo/pregwomen-uscases.html>

# CDC

- Outcomes of Pregnancies with Laboratory Evidence of Possible Zika Virus Infection in the United States, February 7, 2017
  - Completed Pregnancies with and without birth defects (1,047)
  - **Liveborn with birth defect (43)**
  - Pregnancy losses with birth defect (5)

CDC, Outcomes of Pregnancies with Laboratory Evidence of Possible Zika Virus Infection in the United States, 2016-2017  
<https://www.cdc.gov/zika/geo/pregnancy-outcomes.html>

# Live-Born Infants

- Liveborn infants with birth defect **43** (February 7, 2017)

# New Jersey Experience

- NJ was one of the 1<sup>st</sup> States to get their United States Zika Pregnancy Registry up and running.
- Efforts are a collaboration between several different departments including Reproductive & Perinatal Health Services, Early Identification and Monitoring and Center for Disease Services.
- Evolving evidence and guidelines.

# Where to find information about Zika in your state

## **NJ 24/7 Zika Call Center**

**1-800-962-1253**

DOH & NJ Poison Information and Education System partner to open call line.

Know Before You Go...

**#ZapZika**



- ❖ Learn where Zika is active
- ❖ Use insect repellent
- ❖ Wear long sleeves and pants



# Clinical Findings

- Arthrogryposis
- Clubfoot
- Eye anomalies
- Hearing loss
- Hypertonia
- Hypotonia

Leal et al, 2016; Russell et al, 2016; van der Linden, et al, 2016

# Clinical Findings

- Irritability
- Microcephaly and other serious brain anomalies
- Seizures
- Spasticity
- Sucking impairment
- Swallowing dysfunction

# Clinical Findings

- Moore and colleagues did a comprehensive review to evaluate what the evidence says about the pattern of anomalies for infants with congenital Zika infection
  - Brain
  - Eyes
  - Muscles and joints

Moore et al. (2016). Characterizing the pattern of anomalies in congenital Zika infection for pediatric clinicians. *JAMA Pediatrics*.

# Pattern of anomalies

Found 5 features rarely seen with other congenital infections or are unique to congenital ZIKV infection

1. Severe microcephaly with partially collapsed skull
2. Thin cerebral cortices with subcortical calcifications
3. Macular scarring and focal pigmentary retinal mottling
4. Congenital contractures
5. Marked early hypertonia and symptoms of extrapyramidal involvement

# Growing Up AFTER ZIKA

We are still learning about Zika virus and how it affects pregnancy. We hope to find answers that will help inform care for children exposed to Zika in the womb.

## Zika's Effects on the Developing Brain

Infants exposed to Zika in the womb can be born with a small head, a condition called microcephaly. But a small head is only the most visible result. Researchers are finding that Zika also can affect the structure and function of a baby's brain, regardless of head size.



Healthy brain



Microcephaly

Zika disrupts cells in the developing brain so that the brain and head do not reach full size.



Brain calcifications

Calcium builds up in brain tissue and interferes with brain function.



Enlarged ventricles

Spaces inside the brain, called ventricles, are too big, leading to fluid buildup (hydrocephalus) and pressure.

Other Zika-associated brain abnormalities include a smooth brain with no or few folds (lissencephaly), the collapse of the skull (fetal brain disruption sequence), an asymmetrical brain, and the absence of some normal brain structures.

The long-term consequences of exposure to Zika in the womb are still unclear. Based on what is known about fetal exposure to Zika and other infections, problems may include:

- Hearing problems
- Vision problems
- Balance issues
- Developmental and learning delays
- Problems swallowing
- Seizures
- Stiffness and impaired movement
- Low birth weight
- Behavioral issues

**NICHD investigates development throughout the entire life process, including fetal development and early childhood.**

Studying Zika and its effects will help us care for children—both now and as they grow—so they can reach their potential for healthy lives. Learn more about NICHD-supported research on Zika virus at [www.nichd.nih.gov/zikaresearch](http://www.nichd.nih.gov/zikaresearch).



NIH

National Institute of Child Health and Human Development



# Implications for Early Intervention Professionals

- Recognize that knowledge about infants with Congenital Zika Virus is limited and still evolving.
- Knowledge about health and developmental outcomes for infants with Congenital Zika Virus (ZIKV) is lacking.

# Implications for Early Intervention Professionals

- Prepare for potential increased demand for services.
- Prepare for cohort of infants and families who may exhibit more intense health and developmental needs than the typical children enrolled in early intervention services.

# Clinical Implications

- Range of findings
- Benefit from expertise of multiple disciplines
- Information Resources
- Checklist for EI Providers

# Clinical Implications

- Family-centered
- Culturally appropriate
- Social determinants of health
- Privacy and confidentiality

# Clinical implications

- Emotional health
- Psychosocial services
- Parent support
- Self-care and respite

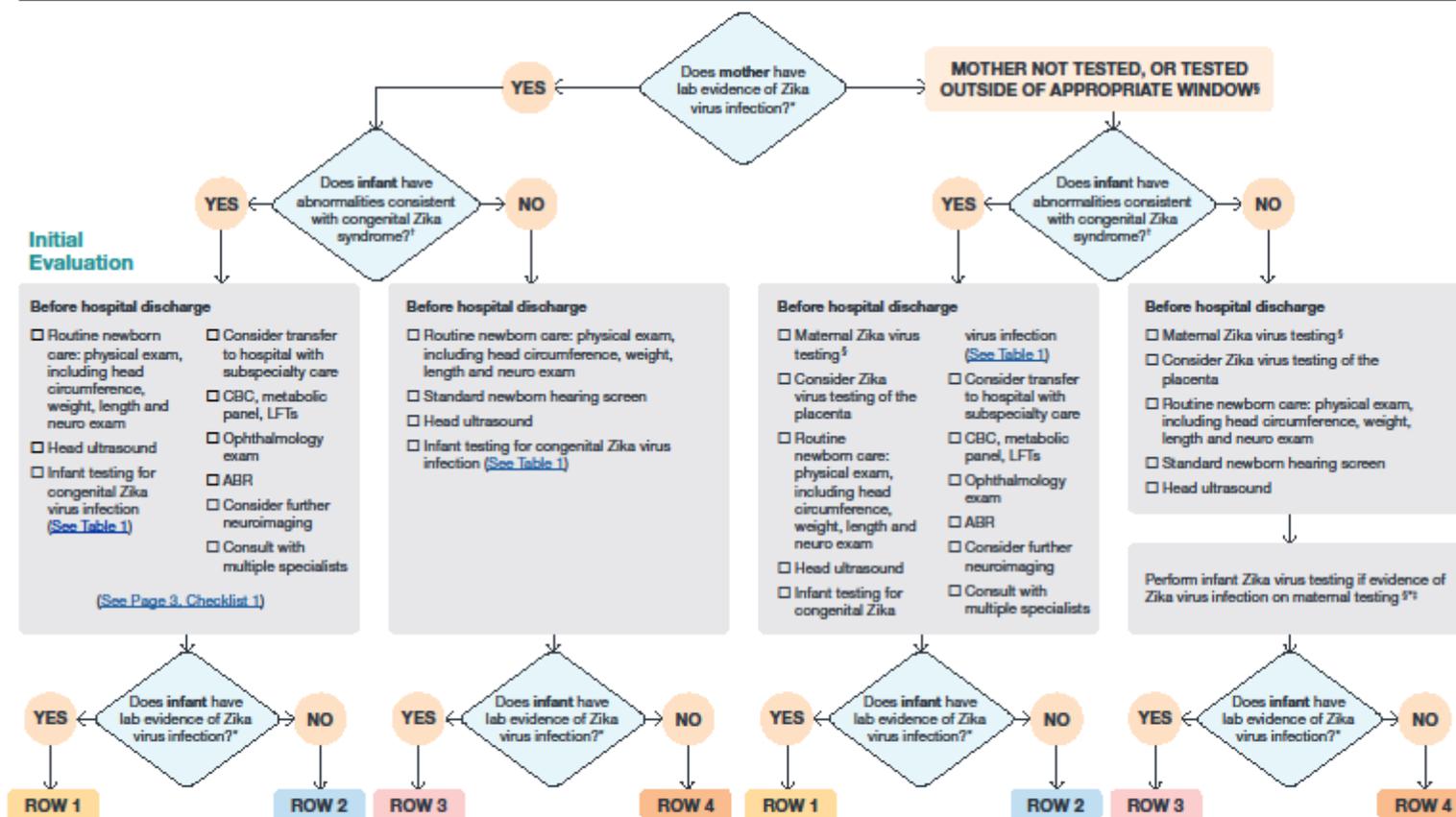
dos Santos Oliveira, S.J.G., de Melo, E.S., Reinheimer, D.M. et al. Arch Womens Ment Health (2016) 19: 1149. doi:10.1007/s00737-016-0654-0; Porter & Mimm, 2017

# Clinical Implications

- Growth parameters
- Hearing
- Vision
- Nutrition, feeding, breastfeeding
- Irritability
- Sleep
- Muscles and joints
- Safety



# INITIAL EVALUATION AND OUTPATIENT MANAGEMENT DURING THE FIRST 12 MONTHS OF LIFE FOR INFANTS WITH POSSIBLE CONGENITAL ZIKA VIRUS INFECTION



Follow management and follow-up recommendations indicated in Outpatient Management Checklist

# MEASURING HEAD CIRCUMFERENCE



- Use a measuring tape that cannot be stretched
- Securely wrap the tape around the widest possible circumference of the head
  - » Broadest part of the forehead above eyebrow
  - » Above the ears
  - » Most prominent part of the back of the head

- Take the measurement three times and select the largest measurement to the nearest 0.1 cm
- Head circumference measurements should be taken on the first day of life because commonly-used birth head circumference reference charts by age and sex are based on measurements taken before 24 hours of age

For more information: [www.cdc.gov/zika](http://www.cdc.gov/zika)



U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

# Policy Implications

- Capacity and resource assessment
- Screening and rescreening; track and follow
- 'ZIKV' Cohort
- Severe Deficits
- Transition planning
- Palliative and hospice care
- Protection of childbearing age staff and parents

# Research Implications

- Improve understanding of the long-term outcomes for infants exposed to Zika virus in utero (Oussayef et al, 2016)
- Short-term and longer-term developmental outcomes
- Intervention case descriptions
  - Irritability
  - Feeding (breastfeeding)
  - Contractures
  - Vision impairment
  - Family support

# Resources

## **CDC Fact Sheets (12/23/16)**

If microcephaly is suspected during pregnancy (a woman would receive with a prenatal diagnosis): <https://www.cdc.gov/zika/pdfs/whattoknow-doctor-suspects-microcephaly.pdf>

If microcephaly or other birth defects consistent with congenital Zika syndrome are apparent at birth (a woman would receive after delivery): <https://www.cdc.gov/zika/pdfs/whattoknow-congenital-zika-syndrome.pdf>

If the baby is born to a mother infected during pregnancy, but the baby looks apparently healthy (a woman would receive after delivery): <https://www.cdc.gov/zika/pdfs/whattoknow-affected-by-zika-no-related-conditions.pdf>

# Resources

- Centro de Recursos sobre Virus Zika <http://zika-virus-resource-center.elsevier.com.br/>
- El virus del Zika: Lo que los padres deben saber <https://www.healthychildren.org/Spanish/ages-stages/prenatal/Paginas/zika-virus.aspx>
- Facts about Microcephaly <http://www.cdc.gov/ncbddd/birthdefects/microcephaly.html>
- MMWR Zika Reports [http://www.cdc.gov/mmwr/zika\\_reports.html](http://www.cdc.gov/mmwr/zika_reports.html)
- United States Zika Pregnancy Registry <http://www.cdc.gov/zika/hc-providers/registry.html>
- Zika Resources for Hispanic Communities <http://espanol.cdc.gov/enes/zika/index.html>

# Resources

- Clinical evaluation and management of infants with congenital Zika infection <https://www.cdc.gov/zika/hc-providers/webcast-clinicalevaluation.html>
- Zika for health care providers <https://www.cdc.gov/zika/hc-providers/index.html>
- Tips for communicating with your baby's health care professional <https://www.cdc.gov/zika/pdfs/tipsforcommunicatingwdoctor.pdf>

# Resources

- Zika Virus and Infants: A Primer [https://www.cdc.gov/zika/pdfs/zika-grand-rounds\\_peds.pdf](https://www.cdc.gov/zika/pdfs/zika-grand-rounds_peds.pdf)
- HRSA Maternal and Child Health Optimizing Family Support for Families of Children with or at-risk for Congenital Zika Virus Infection <https://mchb.hrsa.gov/fundingopportunities/?id=f366b327-d462-4674-8fcb-3ac306a6d5f4>
- Zika Grand Rounds Facilitation Guide [https://www.cdc.gov/zika/pdfs/facilitationguidefaqs\\_pediatricians.pdf](https://www.cdc.gov/zika/pdfs/facilitationguidefaqs_pediatricians.pdf)

# Wrap-up

- Much is still unknown about Zika virus infection.
- Knowledge about health and developmental outcomes for infants with Congenital Zika Virus (ZIKV) is especially limited.
- Early intervention/early childhood professionals need to keep current about the state of the science.
- Early childhood professionals may want to add to the body of knowledge.

# Questions

Sallie Porter [portersa@sn.Rutgers.edu](mailto:portersa@sn.Rutgers.edu)

Nancy Mimm [NaM174@sn.Rutgers.edu](mailto:NaM174@sn.Rutgers.edu)

# References

Centers for Disease Control and Prevention. (2016).

<https://www.cdc.gov/zika/geo/pregnancy-outcomes.html>

Clinical Guidance for HealthCare Providers Caring for Infants and

Children <http://www.cdc.gov/zika/hc-providers/infants-children.html>

Leal, M.C., Muniz, L.F., Ferreira, T.S.A., Santos, C.M., Almeda, L.C., Van Der Linden, V. ...Caldos, S.S. (2016). Hearing loss in infants with microcephaly and evidence of congenital Zika virus infections – Brazil, November 2015 – May 2016. *MMWR*, 65, August 30, 2016

# References

Lopes & Miroff. (2017). The panic is over at Zika's epicenter. But for many, the struggle has just begun. The Washington Post, February 7.

[https://www.washingtonpost.com/world/the\\_americas/the-panic-is-over-at-zikas-epicenter-but-for-many-the-struggle-has-just-begun/2017/02/07/a1f15178-e804-11e6-acf5-4589ba203144\\_story.html?utm\\_term=.42dbc1dcc56f](https://www.washingtonpost.com/world/the_americas/the-panic-is-over-at-zikas-epicenter-but-for-many-the-struggle-has-just-begun/2017/02/07/a1f15178-e804-11e6-acf5-4589ba203144_story.html?utm_term=.42dbc1dcc56f)

Moore, C., Staples, E., Dobyys, R. et al. (2016). Characterizing the pattern of anomalies in congenital Zika infection for pediatric clinicians. *JAMA Pediatrics*.

<http://jamanetwork.com/journals/jamapediatrics/fullarticle/2579543>

Oussayef NL, Pillai SK, Honein MA, et al. Zika Virus — 10 Public Health Achievements in 2016 and Future Priorities. *MMWR Morb Mortal Wkly Rep*. ePub: 30 December 2016. DOI: <http://dx.doi.org/10.15585/mmwr.mm6552e1>

# References

- Porter, S. & Mimm, N. (2017). Infants with Congenital Zika virus infection: A new challenge for early intervention professionals. *Infants & Young Children*, 30, 17-27.  
[http://journals.lww.com/iycjournal/Fulltext/2017/01000/Infants\\_With\\_Congenital\\_Zika\\_Virus\\_Infection\\_A.3.aspx?WT.mc\\_id=HPxADx20100319xMP](http://journals.lww.com/iycjournal/Fulltext/2017/01000/Infants_With_Congenital_Zika_Virus_Infection_A.3.aspx?WT.mc_id=HPxADx20100319xMP)
- Russell, K., Oliver, S.E., Lewis, L., Barfield, W., Cragan, J., Meaney-Delman, D., ... Rasmussen, S. (2016). Update: interim guidance for the evaluation and management of infants with possible congenital Zika virus infection – United States, August 2016. *MMWR Morb Mortal Wkly Rpt.* ePub 19 August 2016. DOI: <http://dx.doi.org/10.15585/mmwr.mm6533e2>
- Steenhuysen, 2016 More work lies ahead to fight Zika, other threats: CDC chief <http://www.reuters.com/article/us-health-zika-frieden-idUSKBN14J1HW>

# References

- van der Linden, V., Filho, E., Lins, O., van der Linden, A., Aragao, M., Brainer-Lima ... Ramos, R. (2016). Congenital Zika syndrome with arthrogryposis: Retrospective case series study. *BMJ*, 354.
- van der Linden V, Pessoa A, Dobyns W, et al. Description of 13 Infants Born During October 2015–January 2016 With Congenital Zika Virus Infection Without Microcephaly at Birth — Brazil. *MMWR Morb Mortal Wkly Rep* 2016;65:1343–1348.  
DOI: <http://dx.doi.org/10.15585/mmwr.mm6547e2>.

Thank you!



## Visit the Websites

- AUCD Website: <http://www.aucd.org>
- EIEC SIG Website: <http://www.aucd.org/eiec>

## Questions about the SIG?

- SIG Co-Chairs
  - Mary Beth Bruder: [bruder@uchc.edu](mailto:bruder@uchc.edu)
  - Corry Robinson: [Cordelia.Rosenberg@ucdenver.edu](mailto:Cordelia.Rosenberg@ucdenver.edu)

## Questions about the Webinar?

- Anna Costalas: [acostalas@aucd.org](mailto:acostalas@aucd.org)

*Please take a few minutes to complete our survey!*