ZIKA: What Family Leaders Working in Public Health Need to Know

September 27, 2016

Welcome! We will begin shortly. Please note:

1. Participant lines are currently muted, and will be unmuted for Q & A near the end of the call. Please mute your line when not speaking by using the mute button on your phone or press *6 to mute/\#6 to unmute.

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Jennifer Bolden Pitre, M.A., J.D
Moderator

- Webinar outline
- Learning Objectives
- Presenter Introductions
Georgina Peacock, MD, MPH, FAAP, is Division Director for the Division of Human Development and Disability (DHDD) at the National Center on Birth Defects and Developmental Disabilities (NCBDDD).

Fernando Ysern, MD, FAAP, is President of the Puerto Rico Chapter of the American Academy of Pediatrics (AAP). Dr. Ysern is currently a medical consultant to the Puerto Rico Health Department’s Vaccine Program and has worked for over 30 years at the Grupo Pediátrico de Caguas. He has served on the Private Payers Advocacy Advisory Committee of the American Academy of Pediatrics and as Chair of the Pediatric Department of the HIMA hospital in Caguas.

Coralidee Jimenez, Family Representative for children with special health care needs (CSHCN) at the Puerto Rico Department of Health. She is the mother of an 11 year old boy with Microcephaly, developmental delays and other conditions.
General overview of how the Zika virus has impacted families in Puerto Rico from a medical practitioners perspective
General overview of how the Zika virus has impacted families in Puerto Rico from a medical practitioners perspective

Fernando J. Ysenn MD, FAAP
President
Puerto Rico Chapter
American Academy of Pediatrics
If you can’t explain it **simply**, you don’t understand it well enough.

– Albert Einstein

ZIKA

Zika Virus: Global Spread

The Zika Virus, traditionally found in Africa and parts of South East Asia, is spreading. See when and where it was detected.
Microcephaly

Development Delays
Irritable Cry
Seizures
Vision Problems
Hearing Deficit
Swallowing disorders
Clubbed Feet
Arthrogryposis
Vectors

Accumulated Confirmed ZIKA cases 22,358
Pregnant women 1,871
67% symptomatic, 33% asymptomatic
>100 with sonographic abnormalities
Hospitalizations 170
Deaths 3
Congenital Birth Defects 1
Guillan-Barré cases 50, 30 ZIKA,
11 other Flavivirus
Puerto Rico's Efforts To Stop Zika Are Hampered By Mistrust

August 10, 2016
Heard on Morning Edition
Grief Cycle

Denial
Anger
Depression
Bargain
Acceptance
It can not happen to me
Yeah but...

It can not happen to me
Prevention

- Vector Control

- Repelents
- Education to the Population
- Prophylactics
Diagnostics

- Clinical
  - Rash
  - Fever
  - Headaches
  - Conjunctivitis
  - Myalgia
  - Arthralgia

- Laboratories
  - < 2 weeks
    - rRT-PCR
      - Real-Time Reverse Transcription-Polymerase Reaction
    - Trioplex
      - Authorized by the FDA under the Emergency Use Authorization (EUA)
      - Distinguishes between ZIKA, Dengue & Chikungunya
  - > 2 weeks IgM
    - No IgG tests available
    - Rapid office test under evaluation
Management

Post Natal Exposure

Support Management
- Antipyretics
- Analgesics
- Antipruritic

Avoid spreading the virus
Family Orientation
Evaluation according to Bright Futures
Registry for ZIKA + children
Thank you for your time

Coraladee Jimenez
PUERTO RICO AND COMMUNITY FACING ZIKA

Family Representative
CSHCN Title V
Mother of a child with microcephaly and multiple conditions
Felix was born
Immediately transfer to NICU

- Poor sucking
- Hypoactive
- Low weight
- Microcephaly
- Micrognathia

PAIN
Denial
Rage
Guilt
PAIN
PAIN
PAIN
PAIN...
AFFECTED AREAS:

- Head shape and size
- Global Developmental Delay
- Severe intellectual disability
- Seizures
- Hearing Loss
- Visual problems
- Non verbal
- Dysphagia
- Gross Motor skills
- Fine Motor skills
- Assistance in all areas
- Frequently sick (hospitalization)
Basic services for my newborn and for a child with multiple conditions:
Needed, needs and will need

- Pediatrician (not any pediatrician)
- Early Intervention
- Cardiologist
- Oxygen tank
- Orthopaedist
- Oftalmologist
- Audilogist
- ENT
- Neurologist
- "EEG"
- "CT"
- "MR/"
- ‘Special Helmet’
- Routine labs.
- Especialzad labs.
- Vision test
- Eyeglasses
- Hearing test
- Swallowing test
- Hearing aid
- Special milk
- Thikening for liquids
- Neurosurgeon

- Genetist
- Psicologist
- Psychiatrist
- Special Education
- Asistent at classroom
- Transportation to and from school to:
  - Physical Therapy
  - Occupational Therapy
  - Speech and Language therapy
- Psicological Therapy
- Medicines
- Levels of medicines(labs)
- Diapers
- Special chair at school
- Transportation chair
- Communication and assistive devices
  - Special spoon
  - Special drinking cup
- Equipment for hands and feet
- AND MORE…
Challenges:

• Access to specialist and sub specialist
  ➢ Pediatric Neurologist
  ➢ Genetist
  ➢ AND...

• Access to specialized services
  ➢ Therapy
  ➢ Specialized studies

• Transportation

• Especial Education
Decided to Act

- Family support groups
- Community based organizations
- Orientations
- Trainings
- STARTED WORKING AS A FAMILY REPRESENTATIVE

Presentations with Public Health Emergency and Preparedness team of Puerto Rico Department of Health

- Universities
- Faith based organizations at different municipalities
  - Pastors
  - Epidemiologist
- Municipalities staff
- Title V staff and families
PR Department of Health
Youth Advisory Council
Who are they and where are from?

14 to 22

Meeting with Dra. Brenda Rivera, State epidemiologist, receiving update Zika information

Arbovirus workshop by Bioceramic staff of the PRDH
What are we doing in the PRDOH?

- Recruiting new and specialized staff for all 7 regions
- Identifying specialist in each region
  - Neurologist
  - Audiologist
  - And more...
- Training staff in birth hospitals
- Promoting and educating on prevention

*7 REGIONS*
Survellaince Systems PRDH:

- Zika Active Pregnancy Surveillance System
- (ZAPSS)
- Birth Defects Surveillance and Prevention System
- Guilliam Barre Syndrome Surveillance System
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Muchas Gracias!
Phone lines will be opened to take questions.

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