



## 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.



**Coralaidée 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.



Georgina Peacock, MD, MPH, FAAP



Fernando Ysern, MD, FAAP

**General overview of how the  
Zika virus  
has impacted families  
in Puerto Rico  
from a medical practitioners  
perspective**



Fernando J. Ysern MD, FAAP  
President  
Puerto Rico Chapter  
American Academy of Pediatrics

## **General overview of how the Zika virus**

**has impacted families**

**in Puerto Rico**

**from a medical practitioners  
perspective**



Fernando J. Ysern MD, FAAP  
President  
Puerto Rico Chapter  
American Academy of Pediatrics

## **General overview of how the Zika virus**

1

**has impacted families**

4

**in Puerto Rico**

2

**from a medical practitioners  
perspective**

3

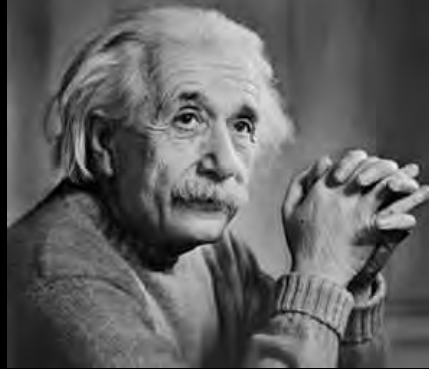


Fernando J. Ysern MD, FAAP  
President  
Puerto Rico Chapter  
American Academy of Pediatrics

If you can't explain it **simply**, you  
don't understand it well enough.

– Albert Einstein

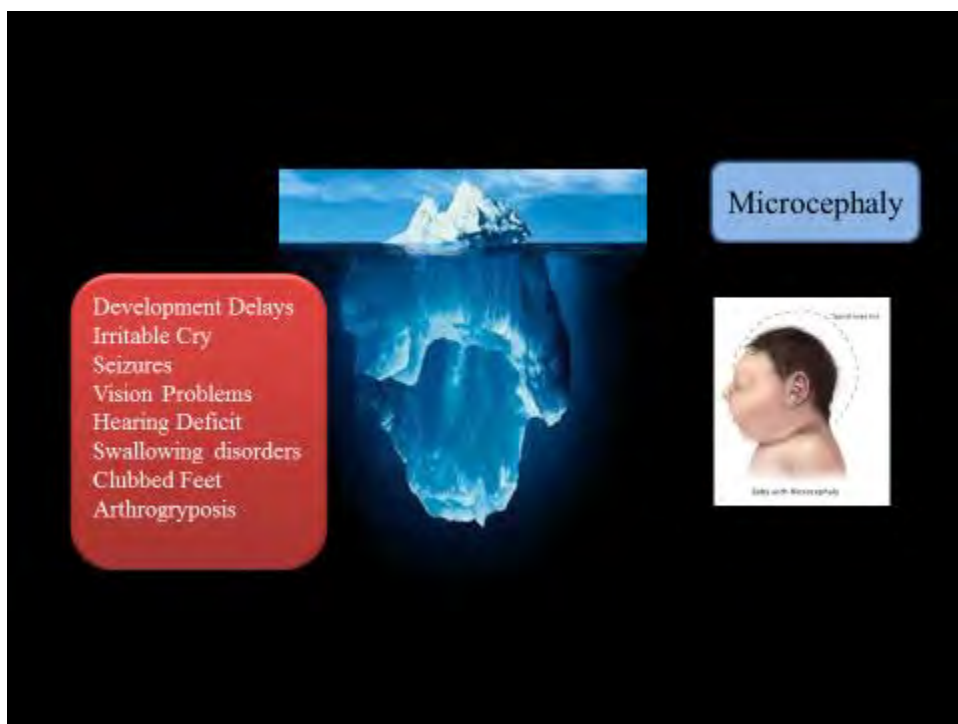
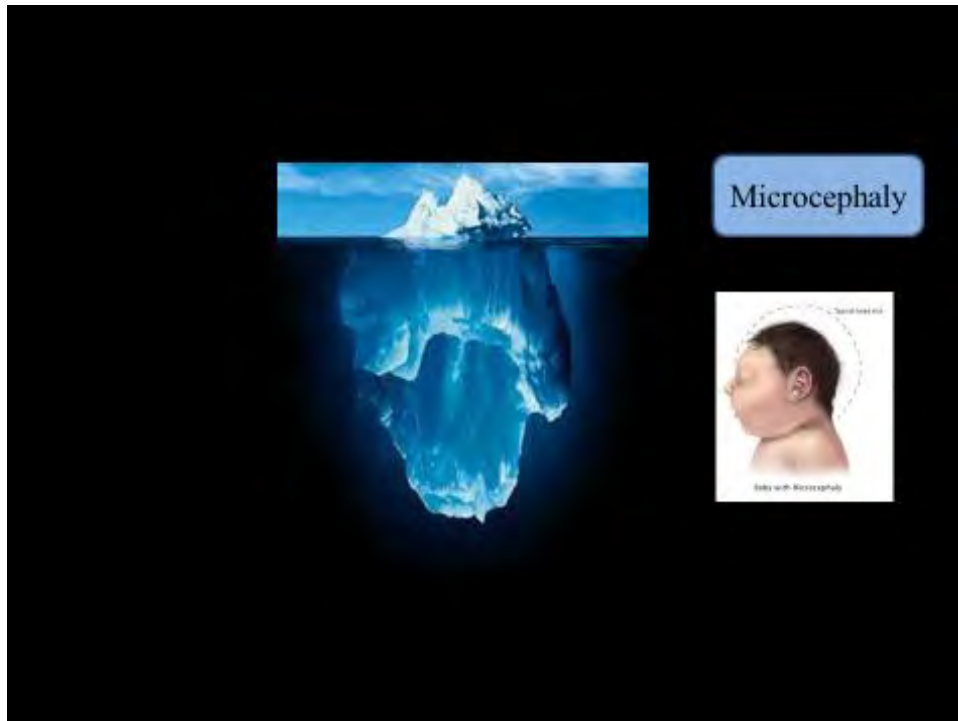
**ZIKA**



### 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.







CHARLES DICKENS  
*A Tale of Two*  
WITH AN INTRODUCTION BY TERRY RIVER

**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, 39 ZIKA,  
11 other Flavivirus



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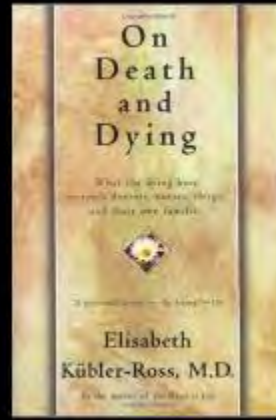


## Puerto Rico's Efforts To Stop Zika Are Hampered By Mistrust

August 10, 2016  
Heard on [Morning Edition](#)

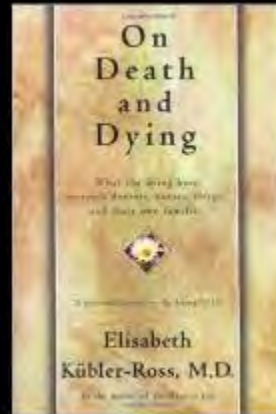






## Grief Cycle

Denial  
Anger  
Depression  
Bargain  
Acceptance



## Grief Cycle

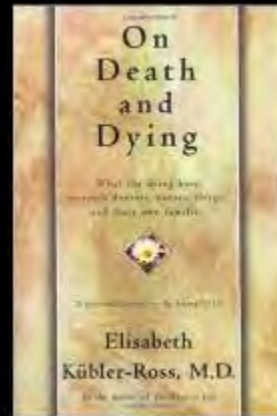
Denial

Anger

Depression

Bargain

Acceptance



**It can not  
happen to  
me**

## Grief Cycle

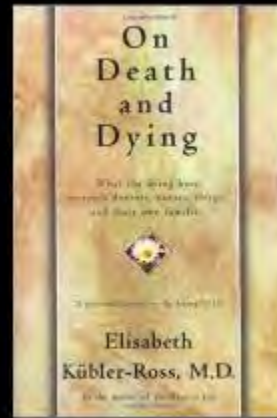
Denial

Anger

Depression

Bargain

Acceptance



Yeah but...

**It can not  
happen to  
me**







## Prevention

- Vector Control



## Prevention

- Repelents
- Education to the Population
- Prophylactics



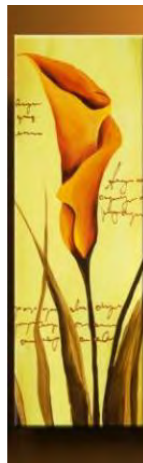


## Prevention



## Diagnostics

- Clínicl
  - Rash
  - Fever
  - Headaches
  - Conjunctivitis
  - Myalgia
  - Arthralgia



### • Laboratories

- < 2 weeks
  - rRT-PCR
    - Real-Time ReverseTranscription-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



## Managment

Post Natal Exposure

### Support Management

- Antipyretics
- Analgesics
- Antipruritic

Avoid spreading the virus

Family Orientation

Evaluation according to

Bright Futures

Registry for ZIKA + children





Management

Pre Natal Exposure







Thank you  
for your  
time



FAMILY VOICES<sup>®</sup> National Center for  
Family Professional Partnerships



Coralaidée Jimenez

# **PUERTO RICO AND COMMUNITY FACING ZIKA**

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**Family Representative  
CSHCN  
Title V**

**Mother of a child with  
microcephaly and multiple  
conditions**

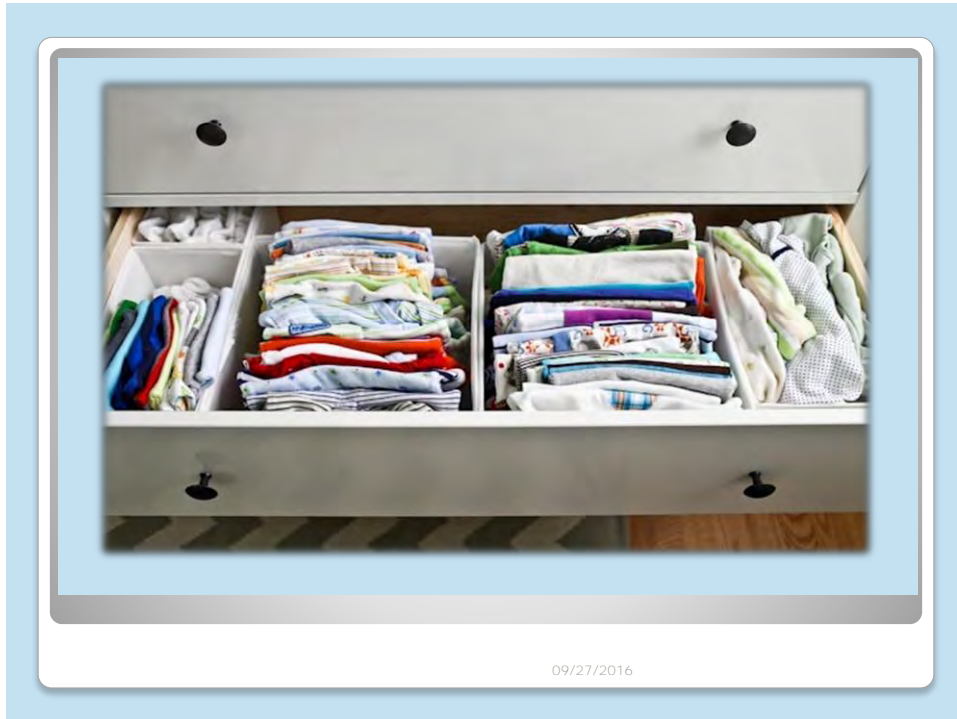
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Immediately transfer to NICU

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

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**PAIN**  
Denial  
Rage  
Guilt  
**PAIN**  
**PAIN**  
**PAIN**  
**PAIN...**

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09/27/2016

**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)

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Basic services for my  
newborn and for a  
child with multiple  
conditions:

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### Needed, needs and will need

- |                                       |   |
|---------------------------------------|---|
| ➤ Pediatrician (not any pediatrician) | ➤ Genetist                              |
| ➤ Early Intervention                  | ➤ Psicologist                           |
| ➤ Cardiologist                        | ➤ Psychiatrist                          |
| ➤ Oxygen tank                         | ➤ Special Education                     |
| ➤ Orthopaedist                        | ➤ Asistent at classroom                 |
| ➤ Oftalmologist                       | ➤ Transportation to and from school to: |
| ➤ Audilogist                          | ➤ Physical Therapy                      |
| ➤ ENT                                 | ➤ Ocupational Therapy                   |
| ➤ Neurologist                         | ➤ Speech and Language therapy           |
| ➤ "EEG"                               | ➤ Psicological Therapy                  |
| ➤ "CT"                                | ➤ Medicines                             |
| ➤ "MRI"                               | ➤ Levels of medicines(labs)             |
| ➤ 'Special Helmet'                    | ➤ Diapers                               |
| ➤ Routine labs.                       | ➤ Special chair at school               |
| ➤ Especializad labs.                  | ➤ Transportation chair                  |
| ➤ Vision test                         | ➤ Communication and assitive devices    |
| ➤ Eyeglasses                          | ➤ Special spoon                         |
| ➤ Hearing test                        | ➤ Special drinking cup                  |
| ➤ Swallowing test                     | ➤ Equipment for hands and feet          |
| ➤ Hearing aid                         | ➤ <b>AND MORE...</b>                    |
| ➤ Special milk                        |   |
| ➤ Thikening for liquids               |   |
| ➤ Neurosurgeon                        |   |

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## Challenges:

- Access to specialist and sub specialist

- Pediatric Neurologist
- Genetist
- AND...

- Access to specialized services

- Therapy
- Specialized studies

- Transportation

- Especial Education



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# DECIDED TO ACT

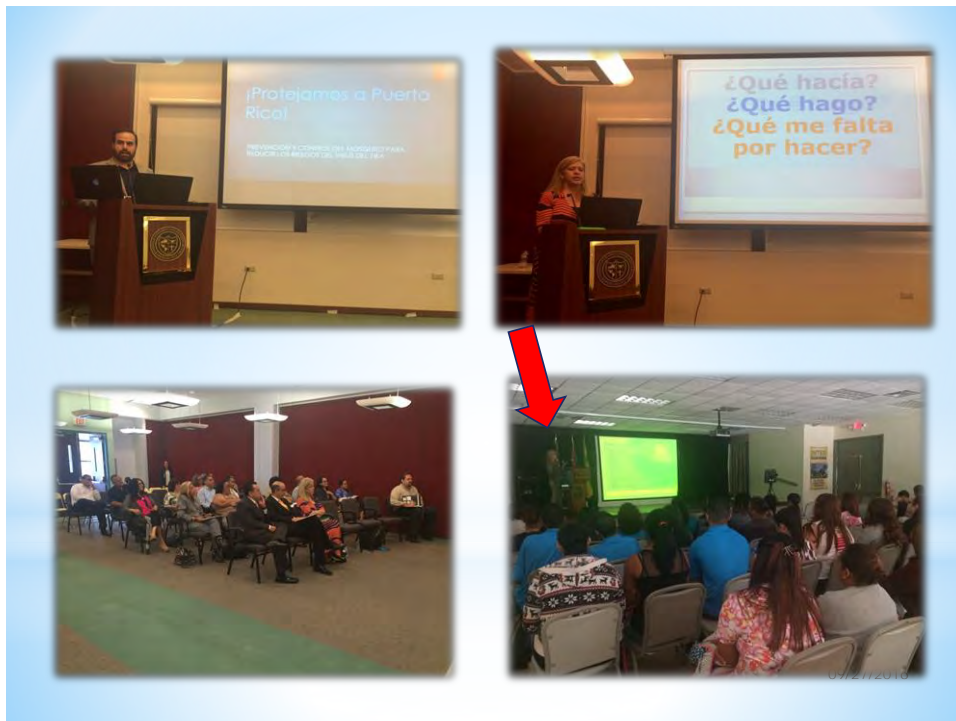
- Family support groups
- Community based organizations
- Orientations
- Trainings
- STARTED WORKING AS A FAMILY REPRESENTATIVE

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

- Universities
- Faith based organizations at different municipalities
  - Pastors
  - Edemiologist
- Municipalities staff
- Title V staff and families

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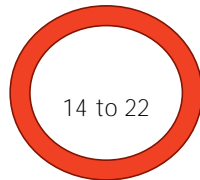
PR Department of Health  
Youth Advisory Council



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## Who are they and where are from?



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Arbovirus workshop by Biosecurity staff of the PRDH



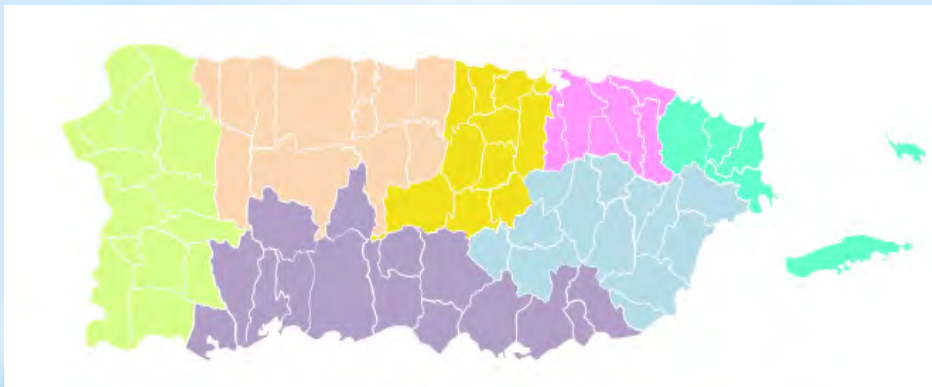
Meeting with Dra. Brenda Rivera, State epidemiologist, receiving update ZIKA information 09/27/2016

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

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\* 7 REGIONS



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### Surveillance Systems PRDH:

- Zika Active Pregnancy Surveillance System (ZAPSS)
- Birth Defects Surveillance and Prevention System
- Guilliam Barre Syndrome Surveillance System

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PREVENTION

AWARENESS

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coralaidée@salud.pr.gov

*Muchas  
Gracias!*

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## Q & A

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