

# *Empowering Families With or at Risk of Congenital Zika Virus Infection*

APNI

Support for Parents of Children with Disabilities  
Coordinator- Roseani Sánchez Algarín  
Med, Instruction and Curriculum

Presented to the  
AAP Zika ECHO  
program on  
April 2, 2018

# APNI

- APNI Inc., which in Spanish stands for Apoyo a Padres de Niños con Impedimentos, (Support for Parents of Children with Disabilities) is a non-profit organization founded in 1977 by a group of parents interested in helping their children receive special education services.
- APNI believes we will all be better if they participate in equal conditions in our society.
- For the past 40 years APNI has represented family voices to assure services are accessible, comprehensive, coordinated, consistent, family centered and evidence based.

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# Who are we?

## APNI

### ***Vision***

- *Ensure that people with disabilities and their families are part of our society and have broad participation in all social, political and economic areas.*

### ***Mission***

- *Provide information, guidance, training, services and support necessary for the protection of rights and full participation of people with disabilities in society.*

# Zika Project

## *Empowering families with or at risk of congenital Zika virus infection*

*The purpose of this project is to empower families of children with or at risk of congenital Zika virus infection. Our priority is for families to obtain the knowledge and skills that allow them to feel confident and competent when relating to or selecting providers of health services for their children.*

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# Our objectives are...

*Focus on families with or at risk of congenital Zika virus infection and/or professionals that work with them.*

- Increase knowledge about the health system, resources in their communities, how to access the system and resources related to the congenital Zika virus infection.*
- Increase the number of professionals with the skills and sensibility to work with families with or at risk of congenital Zika virus infection.*
- Increase the number of families that feel safe and competent when interacting with their children's health providers.*
- Increase the number of families with or at risk of congenital Zika virus infection served by APNI.*

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# What are we doing?

- *Disclosure of services available for these families:*
  - Guide and train families so that they know the services and providers available in their communities.
  - Discuss and explain the "Protocol for the follow-up of infants born from mothers with a laboratory evidence of Zika virus infection during pregnancy" of the Program for Children with Special Medical Needs.
  - Identification of resources and agencies available in the Island that offer services to low-income families.

# What are we doing?

- Increase the number of specialized providers that work with Zika, in our Electronic Directory of Specialists and Resources of Puerto Rico.
- Provide training and guidance to families and professionals in relation to the care of children with or at risk of congenital Zika virus infection.
- Collaborate on referrals of new cases to the Children with Special Medical Needs Program and the Early Intervention Program at the Department of Health of Puerto Rico.

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Services  
available

*Empowering families with or at risk  
of congenital Zika virus infection*



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Department of  
Health of PR

Division of  
Children with  
Special  
Medical Needs

**PROGRAMA NIÑOS CON NECESIDADES ESPECIALES DE SALUD**  
División Niños con Necesidades Médicas Especiales

**Vigilancia del Desarrollo y  
Coordinación de Servicios**

**Para Infantes y Andarines Nacidos de Madres con Evidencia de  
Laboratorio de Infección por el Virus Zika durante el Embarazo**



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Protocol for  
children born  
to mothers  
who tested  
positive to Zika  
virus during  
pregnancy

## Vigilancia del Desarrollo y Coordinación de Servicios

Para Infantes y Andarines

Nacidos de Madres con Evidencia de Laboratorio  
de Infección por el Virus Zika durante el Embarazo



PROGRAMA NIÑOS CON NECESIDADES ESPECIALES DE SALUD  
División Niños con Necesidades Médicas Especiales  
787-765-2929 Ext. 4587 Fax 787-522-3953



DEPARTAMENTO DE SALUD

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# Protocol for children born to mothers who tested positive to Zika virus during pregnancy

## Protocolo para el seguimiento ambulatorio hasta los 3 años

Procedimiento o Prueba	2 meses	3 meses	6 meses	9 meses	12 meses	18 meses	24 meses	30 meses	36 meses
Circunferencia de la cabeza (centímetros)	*		*	*	*	*	*	*	*
Largo (centímetros)	*		*	*	*	*	*	*	*
Peso (kilogramos)	*		*	*	*	*	*	*	*
Cuestionario Edades y Etapas ASQ-3	*		*	*	*	*	*	*	*
Cuestionario Edades y Etapas ASQ-SE-2	*		*	*	*	*	*	*	*
M-CHAT R/F						*	*		
Revisar resultado de:									
<ul style="list-style-type: none"> <li>Cernimiento Auditivo Neonatal (verificar que fue mediante ABR)</li> <li>Evaluación audiológica ABR en el primer mes (en casos de diagnóstico de infección congénita por Zika, referir si no se realizó)</li> <li>Evaluación oftalmológica en el primer mes de edad (referir si no se realizó)</li> </ul>	*								
Evaluación audiológica				* <sub>1</sub>		*		*	
Evaluación oftalmológica		* <sub>2</sub>	* <sub>3</sub>			* <sub>4</sub>		* <sub>4</sub>	
Coordinar evaluación audiológica	✓				✓		✓		
Coordinar evaluación oftalmológica	✓				✓		✓		

### Notas:

1. Evaluación audiológica mediante audiometría conductual a los 7-9 meses de edad de desarrollo, de no ser posible evaluación utilizando potenciales auditivos evocados.
2. Re-evaluación oftalmológica para los infantes con anomalías congénitas y evidencia de laboratorio para infección por el virus Zika, si la evaluación del primer mes fue normal.
3. Re-evaluación oftalmológica para todos los infantes de madres con evidencia de infección por el virus Zika durante el embarazo.
4. Re-evaluación oftalmológica si las evaluaciones anteriores fueron normales.

Si opta por no beneficiarse de los servicios de este Programa asegure que su pediatra o médico primario utilice este protocolo para el seguimiento de su bebé durante los primeros 3 años de vida.

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Department of  
Health of PR

Early  
Intervention  
Program

# Programa de Intervención Temprana “Avanzando Juntos”



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Spina Bifida  
Association

# Asociación de Espina Bífida e Hidrocefalia



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# Electronic Directory of Specialists and Resources of Puerto Rico



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# Electronic Directory of Specialists and Resources of Puerto Rico

- As a Parent Information Center we recognize the great need that exists to make more accessible, agile and quick the search for available and updated services for our population with disabilities. That is why we have given ourselves the task of creating an Electronic Directory of Resources and Services that serves as a tool in the search for service providers. At this moment, we have 3,205 providers and resources available for families and professionals.
- Note after the passage of hurricanes Irma and María, we are in the process of purging the Directory since many of these specialists have left Puerto Rico or are not yet operating

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# Electronic Directory of Specialists and Resources of Puerto Rico

- Some of the resources that you can find in the Electronic Directory are:
  - Medical Specialists (Neurologists, Geneticists, Psychiatrists, Endocrinologists, Infectologists, Gastroenterologists, Nutritionists, others)
  - Service Centers (TH, TO, TF, Psychological Services)
  - Public and private schools
  - Centers specialized in Autism
  - Medical Plans Covers
  - Parent Support Networks
  - Early Head Start and Head Start Programs and Private Preschool Centers
  - Care Centers / Child Care

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Where do you find it?

The screenshot shows the APNI website (apnipr.org) with a navigation menu. A red circle highlights the 'Boletines' dropdown menu, which contains the following items:

- Directorio de Especialistas y Cursos de Puerto Rico
- GUÍA PARA LA IDENTIFICACIÓN TEMPRANA DEL TRASTORNO DEL ESPECTRO DEL AUTISMO
- UN GRAN HERMANO
- Enlaces de apoyo
- Material Informativo
- RECLAMACIÓN DE DAÑOS EN EL PLEITO ROSA LYDIA VELEZ VS. DEPARTAMENTO DE EDUCACIÓN
- Formulario de Querrelas / Remedio Provisional
- Testimonios

The website header includes the APNI logo, the tagline 'APOYO A PADRES DE NIÑOS CON IMPEDIMIENTOS', and navigation links: 'Quiénes somos', 'Proyectos', 'Información', 'Contáctanos', and 'Actividades'. A search bar with the phone number 787-763-4665 is also present. The main banner features the text 'Adiestramientos Online y Webinar' over an image of hands on a laptop. At the bottom, there is a green banner for hurricane relief with the text 'Support the victims of hurricane Irma & María in Puerto Rico' and 'DONATE: Banco Popular of P.R. Account Number 032-381468 Route Number 021502011'. It also lists contact information: 'mensaje@apnipr.org', 'Check or money order: P.O. Box 21280, San Juan, P.R. 00928-1280', and the phone number '787 763 4665'.

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# Information

- APNI Executive Director  
Mrs. Celia Galán  
[centroinfo@apnipr.org](mailto:centroinfo@apnipr.org)
- Coordinator of ZIKA Project  
Roseani Sanchez  
[rsanchez@apnipr.org](mailto:rsanchez@apnipr.org)  
Tel. 787-763-4665 o al 787-250-4552
- Facebook:  
APNI-Apoyo a Padres  
<https://www.facebook.com/APNI.Apoyo/>
- Webpage:  
[www.apnipr.org](http://www.apnipr.org)

“This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). Family Professional Partnership/CSHCN with the grant number H84MC30786. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.”

Questions?



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Thank you!!!



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