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 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.
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.

Apoderando familias con o en riesgo de infección congénita ZIKA
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.
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.
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.

Apoderando familias con o en riesgo de infección congénita ZIKA
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.
Empowering families with or at risk of congenital Zika virus infection

Services available

Apoderando familias con o en riesgo de infección congénita Zika
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

Apoderando familias con o en riesgo de infección congénita ZIKA
Protocol for children born to mothers who tested positive to Zika virus during pregnancy
Protocol for children born to mothers who tested positive to Zika virus during pregnancy

### Protocolo para el seguimiento ambulatorio hasta los 3 años

<table>
<thead>
<tr>
<th>Procedimiento o Prueba</th>
<th>2 meses</th>
<th>3 meses</th>
<th>6 meses</th>
<th>9 meses</th>
<th>12 meses</th>
<th>18 meses</th>
<th>24 meses</th>
<th>30 meses</th>
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<tbody>
<tr>
<td>Circunferencia de la cabeza (centímetros)</td>
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<td>Cuestionario Edades y Etapas ASQ-3</td>
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<td>• Cernimiento Auditivo Neonatal (verificar que fue mediante ABR)</td>
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<td>• Evaluación audiológica ABR en el primer mes (en casos de diagnóstico de infección congénita por Zika, referir si no se realizó)</td>
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<td>• Evaluación oftalmológica en el primer mes de edad (referir si no se realizó)</td>
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**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.

Apoderando familias con o en riesgo de infección congénita Zika

[Logo: ZIKA APNI]
Department of Health of PR

Early Intervention Program

Programa de Intervención Temprana “Avanzando Juntos”

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Asociación de Espina Bífida e Hidrocefalia

Apoderando familias con o en riesgo de infección congénita ZIKA
Electronic Directory of Specialists and Resources of Puerto Rico

Apoderando familias con o en riesgo de infección congénita ZIKA
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.
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
Information

- **APNI Executive Director**
  Mrs. Celia Galán
  centroinfo@apnipr.org

- **Coordinator of ZIKA Project**
  Roseani Sanchez
  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

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Questions?

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Thank you!!!