



Colloquium

Ethical Aspects for Patients' Involvement in Research:

The Case for Establishing a Patient Centered Research Agenda for A Zika and Emerging Health Threats

Friday, August 31, 2018

Verdanza Hotel; Carolina, PR

Event overview

The purpose of this event is to disseminate the results of the work done and share available research results while giving researchers, clinicians, patients and community members.

Event Objectives

- To revisit and train participants in Patient Centered Outcome Research as a responsible and ethical research model
- To disseminate the results of research work done related to Zika
- To share about services for pregnant women and babies with ZVD in Puerto Rico

Audience

- Researchers, patients and stakeholders interested, affected or participating in Zika projects, programs or research
- Healthcare professionals who service pregnant women and children.
- Potential researchers in PCOR
- Active and organized patients' groups or communities who are potential participants in PCOR

Annotated Agenda

8:00 am - Breakfast and Registration

8:30 AM - Call to Order

8:40 AM - Welcome and Overview of the Agenda - Ms. Mariela Rodríguez

Key historical background, Colloquium's objectives and overview of the Agenda

9:00 AM - Zika Research Agenda Update – Ms. María Levis

Description of the Zika Research Agenda; expectations for research; type of research expected; defining and explaining what is PCOR, CER and PRO and how they differ from traditional research; actual results.

9:30 AM - Plenary Session: Why Involve Patients in Research? Why Ask Them What Matters? – Dr.

Frances García

A discussion of why PCOR and PRO is the ethical way of doing research

10:00 AM - BREAK



TRACK A - About PCOR; Moderator: Ms. Natacha Suárez (Patient)

- **New Methodologies: Have I Really Got Rid of my Old Research Habits? Dr. Enid García, Dr. Carmen Zorrilla**

Doctors Zorrilla and Garcia spoke about changing focus and viewing patients' as experts in their diseases and experiences. They emphasized that there is a process of un-learning traditional components of research and being open to new ways to collect data and design research. They showcased PCOR as a collaborative model.

- **How does IRB apply to Patient Centered Outcome Research? - Dr. Vanessa Sepulveda**

The speaker informed that the IRB and other institutions are gradually accepting PCOR. Its nature poses a challenge in evaluating each research initiative and needs for new protocols and federal guidance. They have recently developed a Patient Engagement Panel (PEP) to help define the role of patients in research and guide the IRB on how to engage.

- **Tools for measuring patient engagement and partnership – Ms. María Levis**

Mrs. Levis spoke on Impactivo's experience in measuring patient engagement and strategies for engagement. She used the Conferences excellent patient attendance as an example to prove that there are many lessons to be learned, but great benefits to reap from that growth. It is important to always have a link with the community, be very transparent and clear on the purpose of the interactions. An effective way to engage is to be consistent on information provided and time investment. For patients to participate, information must always be relevant. To measure engagement, one must take time and effort to survey expectations, design outcome measures and then carry out evaluation surveys to obtain feedback, improve and reimplement for different projects.

TRACK B - For Parents; Moderator: Dr. María del Rosario González

- **Services Available for babies born with ZVD - Dra. Inés García**

Doctor Garcia spoke about the importance of Zika and other screening tests and how to reach them. She let the audience know about federal funds aimed at providing services for pregnant women, even if they are not showing symptoms. She introduced participants to the programs available through the government and other groups. The program of which she spoke of did not need referrals.

- **Know the Laws, Know your Child's Rights? A Patient's Perspective – Ms. Marta González**

Marta, a patient, used this platform to share her experience, difficulties, successes and lessons learned having had a child with special needs and many birth complications. Now grandmother to a Zika-exposed child, she also informed the audience of several governmental aids and services available but unknown to most people.

- **Early Stimulation and Interventions at home Dr. Elizabeth Pagan**

With many years of experience with pediatric patients, Dr. Pagan shared with the parents an overview of the child's developmental phases from the prenatal period and well into childhood. Using simple and plain language, she explained what developmental milestones and indicators are and how one should monitor the developmental progress of our child at home. Although every child is different, developmental milestones guide us. She shared strategies to stimulate child's development from the comfort of a safe space such as home.

11:15 AM - Panel: Ethics of responsibility on the subject of Zika and pregnant women; Moderator: Dr. Lourdes Soto. Speakers: Dr. Waleska Sanabria, Dr. Vicent Sifres, and Dr. Marieli Rivera

The speakers referenced their experience from the 2016 outbreak to the present day focusing on ethical aspects and the vulnerability and stigma of pregnant women affected by Zika. Some background of the disease was provided, context on the ethical aspects and also, they shared recommendations on how research should be carried out, moving forward to another similar situation.

12:00 PM - LUNCH

12:50 PM - Carrying Out Patients and Stakeholders Engagement Dr. María del Rosario González

Small Group Work Division & Reports. Participants worked in group establishing a plan to advance PCOR and signed a personal commitment to advance the patients' voice in research.

1:45 PM - Panel: Success Stories I – Community Outreach Ms. Ivette Segui, MPH - ASPPR

Primary Care Centers Outreach Coordinators share their success stories (3)



2:15 PM - BREAK

2:30 PM - Panel: Success Stories II – Research Efforts Mr. Ignacio Alvarez

Research partners shared their success stories with participants:

- *Dr. Inés García – summary of all projects in which the Neonatal Group has become involved*
- *Dr. Carmen Zorrilla- summary of all projects she has engaged in at the U of Puerto Rico School of Medicine*
- *Dr. Luzeida Vargas – summary of all efforts at the Ponce School of Medicine*
- *Dr. Carmen Velez - summary of projects at the Puerto Rico Brain Trust and PROTECT Project*

3:15 PM - Plenary Session: Communications during Public Health Emergencies – Ms. Lisa Orloff

As founding member of Word Cares Center, Ms. Orloff shared the emergence and importance of capacitating all persons to be able to aid themselves and others during and following a disastrous event. She spoke of means, types, and styles of communication, the complexities of the communication systems and how to deal with those challenges. She pointed out how communication structures and styles vary depending on the kind of audience giving out the message and receiving the messages, stressing its importance on crisis situations.

4:05 PM - Wrap Up & Evaluation Dra. María del Rosario González

The activity ended on time and evaluations were collected from the audience. All participants were prompted to stay for the networking session.

4:30 PM - NETWORKING