

**POGO'S CENTRAL AMERICAN PEDIATRIC ONCOLOGY RESEARCH INITIATIVE (C.A.P.R.I.):  
A COOPERATIVE EFFORT TO IMPROVE OUTCOMES FOR CHILDREN WITH CANCER IN CENTRAL AMERICA**

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**THE ISSUE**

Almost 90% of all children with cancer live in developing countries where resources for diagnosis and treatment are all too often inadequate.

Prior to POGO's Central American Pediatric Oncology Research Initiative (CAPRI), survival rates in developing countries, such as those in Central America and Eastern Europe, were a disappointing 35% compared to 80% in North America and Western Europe. If left unchecked, this survival gap was sure to increase.

It has been found that the main reasons for the difference in survival rates are abandonment of therapy, infection, and other treatment-related complications. Contributing to this are the long distances families must travel to reach a treatment centre, as well as parents being overwhelmed and under-informed about the disease, infection control, and their ability to navigate within the healthcare system.

**WHAT CAN BE DONE**

Partners in the CAPRI collaboration (Pediatric Oncology Group of Ontario (POGO), St. Jude Children's Research Hospital, the Monza International School of Pediatric Hematology/Oncology (MISPHO) and the Asociación Hemato-Oncológica de Centroamérica (AHOPCA)), identified the following steps as significant means to address the low survival rate for children with cancer:

1. Prevention of abandonment by:
  - ⊙ Reducing travel times to treatment centres;
  - ⊙ Providing accommodation, meals and other support during hospitalization;
  - ⊙ Orienting parents about the disease and the multidisciplinary healthcare team;
  - ⊙ Establishing procedures that recognize early signs of abandonment.
  
2. Infection control that includes:
  - ⊙ Development of appropriate policies and procedures;
  - ⊙ An antisepsis and handwashing program that trains doctors, nurses, children with cancer and their parents;
  - ⊙ Construction of residential facilities, "Albergues", for families in each of the centres in Central America, not only to reduce accommodation and food costs to the families, but also to monitor and train parents in the care of their children.
  
3. Improving the quality of treatment by:
  - ⊙ Monitoring adherence to treatment protocols and their impact;
  - ⊙ Developing better therapeutic strategies and measuring their efficacy.

**WHAT POGO IS DOING**

*CAPRI Phase I* addressed the issues of abandonment, infection and the quality of treatment by putting two simple, yet effective programs in place: a data management system implemented in Honduras, Guatemala, Costa Rica, Nicaragua, El Salvador, Panama, & Dominican Republic, and a nursing leadership pilot project in Nicaragua.



## **Data Management**

Measurement of outcomes is central to modern pediatric oncology practice and is a prerequisite to enable the analysis of data and provide targeted interventions that are necessary to improve childhood cancer care in low-income countries. Yet prior to CAPRI, data management was virtually non-existent in Central American countries that comprise the Asociación Hemato-Oncológica de Centroamérica (AHOPCA).

Thanks to POGO, twelve data managers in AHOPCA countries, have been hired and trained. They now record in real time the new diagnoses, number of clinic visits and hospitalizations, selected toxicities, and outcomes such as death from toxicity, relapse, abandonment of treatment, and continuous remission. In addition, they have inputted more than 7000 older hospital records of children and adolescents with cancer that were previously only kept in paper files. This is a precious source of information for guiding further developments.

In 2006, 1048 children and adolescents with newly diagnosed cancer were treated in these centers. All have been registered in the database; Analysis of the survival gap in Honduras indicates that causes for treatment failure after 1 year have decreased from 48% to 28%;

## **Nursing Leadership Pilot Project in Nicaragua**

Thanks to POGO, a model program in nursing leadership was established with the goal to export it to the other members of AHOPCA. Specific components of the program were:

1. Educational intervention with nurses, including education about:
  - ⊙ Communicating with parents under stress
  - ⊙ Orienting parents about the disease and the healthcare system
2. Development of an infection control program that includes establishing:
  - ⊙ Infection control policies & procedures
  - ⊙ A handwashing and antisepsis program focusing on:
    - Washing hands
    - Cancer and infection
    - Body temperature
    - Mouth care
    - Medication administration

Parents have been motivated to collaborate with members of the multidisciplinary team and to conform to infection control practices. Close collaboration between social work and nursing has been established. A manuscript evaluating the success of the project has been written, published and presented at conferences in North America and elsewhere. This is particularly significant because nurses in Central America have never before presented research, let alone in an international forum.