



World Child Cancer
No child should suffer

PROJECT FACTSHEET: AHOPCA - Central America

Project Centres:

Central American Paediatric Haematology-Oncology Association:

Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama & Dominican Republic

Twinning Centre:

St Jude Children's Research Hospital, USA

Other Charity Partners:

St Jude Children's Research Hospital
POGO: Paediatric Oncology Group Ontario

Project Leaders:

Various

Project Mentors:

Dr Scott Howard & Yuri Quintana, St Jude Children's Research Hospital

Start & End Date:

January 2013 - December 2017



Patients at the hospital in Honduras

Background:

The Central American Paediatric Haematology-Oncology Association (AHOPCA) was formed in 1996 as an alliance of paediatric oncology units in Central America. The purpose is education, implementation of uniform treatment regimens and continuous improvement in the quality of care by analysis of outcomes in each centre and in the region as a whole. It includes 8 centres in 7 countries that treat around 1000 children with newly diagnosed cancer each year. Each centre is supported by a non-profit foundation and has a parent group to help improve care and support for families. The project focuses on improving the data management systems of the centres. A data register is crucial to documenting progress and future planning for childhood cancer care. Understanding the scale of the problem results in a reliable record of patient numbers and survival rates.

Key Problems:

- Abandonment of treatment
- Lack of a reliable data management system
- Not enough dedicated data managers
- No salary support for data management staff
- No training programme for data management staff
- Lack of outcome evaluation for the programme

Project Objectives:

- 1) Decrease abandonment of treatment
- 2) Improve patient support and event-free survival
- 3) Increase access to effective psychosocial support
- 4) Establish a reliable database in each centre
- 5) Expand and enhance data management programmes

Key Project Outputs:

- Establish POND database use at the centres
- Support the salary and training of data managers at each site
- Development of a career pathway for data managers in low / middle income countries and a training programme for each step along the pathway
- Lay groundwork for incorporation of salaries in operational budgets of each site
- Use tools to document and improve the services provided to patients and families
- Adapt POND reports to include the psychosocial aspects of the services
- Regular analysis of data quantity and quality
- Regular meetings, online training and mentoring for staff
- Training in psychosocial aspects for professionals, local NGOs and parents

Impact:

- Data managers have stable salary support for 5 years, improving morale and retention
- Data managers have support for ongoing education
- Data managers have a career pathway that allows for education and career advances
- Improved morale due to existence of a career pathway and continuing education
- Accurate numbers of patients treated at each center are available
- Patient outcomes and causes of treatment success and failure are documented
- Interventions can now be tailored to causes of treatment failure
- Effectiveness of interventions to improve care and survival can be measured in real time



A young patient at the AHOPCA project



Data managers at a training course