

***PAHO-IARC Meeting.***  
***Brasilia October, 2009.***

**Improving information on cancer in  
Latin America and Caribbean**

**13-14 October, 2009.**

**Registries in Latin America and the Caribbean  
and its relation to cancer programs**

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**IACR Representant for Latin America.**

## ***My speech is based in information from different sources:***

- The main results of a questionnaire sent to S.A Cancer Registries on May 2007 in order to provide some recent data to the "Working Group on data Production in Cancer Registration in Low and Medium Resource Countries" IARC. Lyon, July 2007
- The results of the IACR questionnaire sent to Central and South America Cancer Registries in April 2009 for the 31 IACR Meeting (New Orleans, May , 2009)
- Main results of the 2nd Meeting of the Cancer Registries Argentine Association held in Bahía Blanca, Argentina, on April 8, 2009.

# **At present in Central and South America, there are 78 Cancer Registries associated to IACR**

- 43 category A: associate
- 12 category I : individual
- 21 category V :voting 27%
- 2 without category
- 11 accepted in CIV IX Ed : 14%

# **In April 2009 I received only 14 replies to the questionnaire of the 78 registries from the IACR list**

- Argentina 5
- Brasil 4
- Guatemala 1
- Perú 2 (one reported that no longer works)
- Uruguay 1

<b>Country</b>	<b>Name</b>	<b>First name</b>	<b>Last name</b>
<b>ARGENTINA</b>	Provincial Tumor Registry Salta City	Gerardo	Arroyo
<b>ARGENTINA</b>	Cancer Registry of Campana City	Roberto	Cianis
<b>ARGENTINA</b>	Provincial Registration of Tumors of Mendoza	Rogelio	Taber
<b>ARGENTINA</b>	Registro de Cancer Santa Fe - RECASFE	Silvia	Audero
<b>ARGENTINA</b>	Registro Poblacional de Cáncer de la Pcia de Tierra del Fuego	Susana Graciela	Ibañez
<b>ARGENTINA</b>	Entre Ríos State Population-Based Cancer Registry	Miguel	Angel Prince
<b>ARGENTINA</b>	Registro de Tumores	Jorge E.	Cura
<b>ARGENTINA</b>	Registro de Tumores en la Infancia	Ricardo	Drut
<b>ARGENTINA</b>	Registro Provincial del Cancer Gonnet	Silvia C.	Bonicato
<b>ARGENTINA</b>	Registro de Tumores de la Provincia de Cordoba	Graciela	Nicolas
<b>ARGENTINA</b>	Registro Oncopediatrico Hospitalario Argentino	Florencia	Moreno
<b>ARGENTINA</b>	Registro de Cáncer de Base Poblacional de la Provincia de Río Negro	Rubén	Kowalyszyn
<b>ARGENTINA</b>	Registro Argentino de Melanoma Cutaneo	Dora	Loria
<b>ARGENTINA</b>	Registro Populacional de Tumores - Provincia de la Pampa	Rubén M.	Molina

<b>ARGENTINA</b>	Centro Privado de Radiaciones	E.N.	Depatto
<b>ARGENTINA</b>	Registro del Cancer del Hospital 'R. Santamarina'	O.	Garcia Allende
<b>ARGENTINA</b>	Cancer Registry of Venado Tuerto City	Joaquin	Sanchez de Bustamante
<b>ARGENTINA</b>	Registro Regional de Tumores del Sur de la Pcia de Buenos Aires	Eduardo	Laura
<b>BARBADOS</b>	The Barbados National Cancer Registry	Ian	Hambleton
<b>BERMUDA</b>	Bermuda Tumour Registry	Katura	Horton-Perinchief
<b>BOLIVIA</b>	Registro de Cancer de la Paz	Jaime L.	Rios-Dalenz
<b>BRAZIL</b>	Population Based Cancer Registry of Federal District	Elza	Pastor Martinez
<b>BRAZIL</b>	Instituto Nacional de Câncer - INCA	Marise	Rebelo
<b>BRAZIL</b>	Hospital-Based Cancer Registry	Claudio Francisco	Cabral
<b>BRAZIL</b>	Registro de Cancer de São Paulo	Fernanda Alessandra	Silva
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de Aracaju	Carlos	Anselmo Lima
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de Manaus	Anassellis	Veiga de Lima
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de João Pessoa	Josefa Angela	Pontes de Aquino
<b>BRAZIL</b>	Registro de Câncer - Minas Gerais	Berenice	Navarro Antoniazzi

<b>BRAZIL</b>	Population-Based Cancer Registry of Curitiba	Cyntia	Asturian Laporte
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de Palmas	Fernando	Pedroso Berdarraín
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de Salvador	Elmando	Sampaio Silva
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de Campinas-SP	Nazira	Mahayri
<b>BRAZIL</b>	Registro de Cancer de Fortaleza	Miren Maite	Uribe Arregi
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de Goiânia	Jose Carlos	de Oliveira
<b>BRAZIL</b>	Registro de Câncer de Base Populacional de Porto Alegre	Paulo Recena	Grassi
<b>BRAZIL</b>	Registro de Cancer de Pernambuco	Albertina Maria	Suliano Brito
<b>CHILE</b>	Registro Regional de Cancer II, Region Antofagasta	Mario	Goycolea Chaparro
<b>CHILE</b>	Valdivia Cancer Registry	Maria	Bertran Vives
<b>COLOMBIA</b>	Registro Poblacional de Câncer de Antioquia	Mary Ruth	Brome Bohórquez
<b>COLOMBIA</b>	Registro Nacional de Cancer	Margarita	Ronderos
<b>COLOMBIA</b>	Registro Poblacional de Câncer del Area Metropolitana de Bucaramanga	Claudia	Janeth Uribe Pérez
<b>COLOMBIA</b>	Cali Cancer Registry	Luis Eduardo	Bravo
<b>COSTA RICA</b>	Costa Rica National Tumor Registry	Adolfo	Ortiz Barboza
<b>CUBA</b>	Registro Nacional de Cancer de Cuba	Yaima	Galán Alvarez

<b>ECUADOR</b>	Registro Nacional de Tumores	Patricia	Cueva Alaya
<b>ECUADOR</b>	Cuenca Tumor Registry	Nicolas	Campoverde
<b>GADELOUPE</b>	Registre des Tumeurs de Guadeloupe	Catherine	Bachellier-Billot
<b>GUATEMALA</b>	Registro Nacional de Cancer - Guatemala	Mynor R	Villeda
<b>GUATEMALA</b>	Registro Nacional de Cancer - Guatemala	Carlos	Waldheim
<b>GUYANA</b>	Registre des Cancers de la Guyane	Saïd	CHEKKOURY
<b>GUYANA</b>	Guyana Cancer Registry	Penelope	Layne
<b>HONDURAS</b>	National Cancer Registry of Honduras	Flora	Duarte
<b>HONDURAS</b>	National Cancer Registry of Honduras	Jacqueline	Figueroa Nuñez
<b>HONDURAS</b>	Liga Contra el Cancer		
<b>HONDURAS</b>	Cancer Registry of the San Felipe Hospital	Hilda Lourdes	Aguilar
<b>JAMAICA</b>	Jamaica Cancer Registry (Kingston and St. Andrew)	Barrie	Hanchard
<b>MARTINIQUE</b>	Registre des Cancers de la Martinique	Moustapha	Dieye
<b>MEXICO</b>	Registro Histopatologico de Neoplasias Malignas	Pablo A.	Kuri
<b>MEXICO</b>	Registro de Cancer de Oaxaca	Vilma Barahona	Matamoros
<b>MEXICO</b>	Directorate of Epidemiology	Pedro	Rizo Rios
<b>NETHERLANDS ANTILLES</b>	Netherlands Antilles Cancer Registry	C.M.D.	Coronel



NICARAGUA	National Cancer Registry of Nicaragua-CNR	Angel	Mendez-Guillén
NICARAGUA	Cancer Registry of León	Ofelia G.	Rojas Berrios
<b>PANAMA</b>	<b>Registro Nacional del Cancer</b>	<b>Plinio</b>	<b>Valdes</b>
<b>PARAGUAY</b>	<b>Registro Nacional de Patología Tumoral</b>	<b>Fernando</b>	<b>Llamosas</b>
<b>PERU</b>	Registro de Cancer de Base Poblacional de Cajamarca	Sonia Díaz	Estacio
<b>PERU</b>	Registro de Cancer de Base Poblacional de Cajamarca	Pedro Leon	Alvarez
<b>PERU</b>	Cayetano Heredia Regional Hospital Piura	Jorge Eduardo	Aliaga Cajan
<b>PERU</b>	Registro de Cancer de Lima Metropolitana	Ebert	Poquioma
<b>PERU</b>	Registro de Cáncer de Trujillo	Pedro F.	Albujar
<b>PERU</b>	Arequipa Poblacional Cancer Registry	Luis	Medina Fernandez
<b>PUERTO RICO</b>	Puerto Rico Central Cancer Registry	Nayda	R. Figueroa
<b>SAINT VINCENT AND THE GRENADINES</b>	<b>St Vincent and the Grenadines Cancer Registry</b>	<b>Ronald J</b>	<b>Child</b>
<b>SURINAM</b>	<b>Pathology-based Cancer Registry</b>	<b>M. Albert</b>	<b>Vrede</b>
<b>TRINIDAD AND TOBAGO</b>	The National Cancer Registry of Trinidad & Tobago	Verónica	Roach
<b>URUGUAY</b>	<b>Registro Nacional de Cáncer de Uruguay</b>	<b>Enrique</b>	<b>Barrios</b>
<b>VENEZUELA</b>	Venezuela Cancer Registry	David	Evans



## South America Cancer Registries Questionnaire Answers - July 2007

	Registries	Active	Registering at present	Search		
		<b>100%</b>		Activ	Passive	Mix
Argentina	Bahía Blanca	si	2003	x		
	(sur de la Pvcia. Bs As)					
	Chaco	si	2002			x
	La Pampa	si	2006-2007			x
	Mendoza	si	2006-2008			x
	Santa Fé	si	2006			x
	ROHA	si	2000			x
Brazil	Tierra del Fuego	si	20006-2007			x
	Camargo	si	2005	x		
	Curitiba	si	2003-2006			x
	Jàu	si	2005-2006	x		
	Jàu - SP	si	2006-2007	x		
	San Pablo	si	2005-2006			x
Colombia	RC-BPBH	si	2002-2003			x
	Cali	si	2006-2007			x
Perú						
	Arequipa	si	2004-2006	x		
	Lima	si	1999-2006	x		

## South America Cancer Registries Questionnaire Answers - July 2007

Countries	Registries	data sent CI in Five Cont. Vol IX	
		yes	no
Argentina	Bahía Blanca	x	
	(sur de la Pvcia. Bs As)		
	Chaco		x
	La Pampa		x
	Mendoza		x
	Santa Fé		x
	ROHA		x
	Tierra del Fuego		x
Brazil	Camargo	x	
	Curitiba	x	
	Jàu	x	
	Jàu - SP	x	
	San Pablo		
	RC - BPBH	x	
Colombia			
	Cali	x	
Perú	Arequipa	x	
	Lima	x	

## South America Cancer Registries Questionnaire Answers - July 2007

Countries	Registries	Do consider that this Registry is working		
		Very Sat	Med. Sat	Seriuos diff
Argentina	Bahía Blanca		x	
	(sur de la Pvcia. Bs As)			
	Chaco		x	
	La Pampa		x	
	Mendoza	x		
	Santa Fé		x	
	ROHA			
Brazil	Tierra del Fuego	x		
	Camargo		x	
	Curitiba		x	
	Jàu	x		
	Jàu - SP	x		
	San Pablo	x		
Colombia	RC - BPBH		x	
	Cali	x		
Perú	Arequipa		x	
	Lima		x	

# **South America Cancer Registries Questionnaire Answers - July 2007**

- **81% have economic difficulties; 50% present difficulties in the lack of understanding on the part of the Health Professionals ; in the data capture ; lack of computerization .**
- **Only 30% receive provintial financial. 50% receive mixed financing .**
- **100% think that it would be useful to have an Association of Cancer Registries of South America.**

✓ Only 25 % of the Cancer Registry's Directors who answered the questionnaire consider that their country have consistent Cancer Control Programs ; 82% consider that it would be useful scientific , technical and financial support

✓ 75% are dedicated exclusively to the recording and Epidemiologist techniques, the rest is inserted in other administrative structures.

✓ 57% have sent the data for publication in Cancer Incidence in Five Continents Vol. IX

✓ Only 50% are involved in investigation tasks.

✓ 38 % evaluate the quality of their data in agreement with the guidelines established by the IARC.

✓ 43% evaluate their work like very satisfactory ; 57% moderately satisfactory

## **II - MAIN OBSTACLES FOUND**

**A) Data collection is not easy at all and sometimes it is very difficult: the Health Systems are most of the times complex. It is frequent to find public health assistance for poor people; Social Securities Systems that are rarely unified. So according to the activity or the union they have independent Social Security**



**In the particular case of our Registry in the city of Bahía Blanca the data are more easily obtained in the public hospitals. They are also better computerized.**

# Republica Argentina, Pcia de Bs. As., Bahía Blanca.



So, as you can see, there is a big difference when you compare the possibility of data capture in South America with for example U K, Australia, Canada or the northern countries who have unified National Health Systems.

**B) The majority of Health Professionals, including Health Officers don't assign importance to good cancer data. In many South America countries emphasis is put in assistance and little effort is made in planning in the long term and prevention.**

Many of South America countries don't have consistent Cancer Programs. At the public level Pap test is offered free of charge but consistent programs are the exception.

**In Argentina until few years, many healths public officers thought that offering free Pap tests they were making an important contribution in Cancer Control. They didn't have at that time incidence figures.**

**When our Registry started in 1989 it showed that at least in our area cervix cancer accounted for less than 7% of invasive cancers among women (so about 3% of the total invasive cancer burden).**

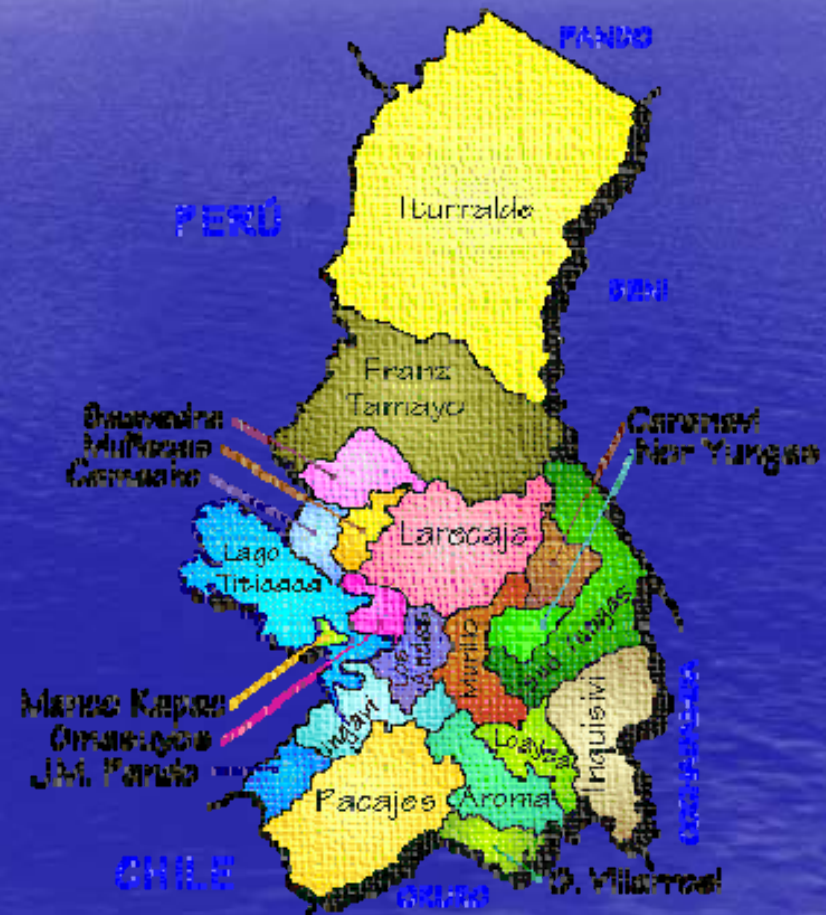
C) Lack of enough economic resources to pay the Registry personnel and to other important items like the possibility of attending scientific meetings, pay scientific publications etc, produces instability of the trained technicians ( this happens to us continuously) with the result that you have to train again and again new people.

Also as Director you have to devote a lot of time to get funding and you diminish time to data analysis and research (and in many cases the Registry Directors have not full time dedication).



## There are in the Region recent examples of economic restrictions as a cause of the stop of Cancer Registration:

- La Paz, Bolivia:2007- La Paz (Bolivia) information sent by Dr. Del Rio Dalenz.



- 2009- Trujillo (Perú) recent information from it historical Director Dr. Pedro Albujaar.



***"2nd Meeting of the Cancer Registries  
Argentine Association held in Bahía Blanca,  
Argentina, on April 8, 2009."***





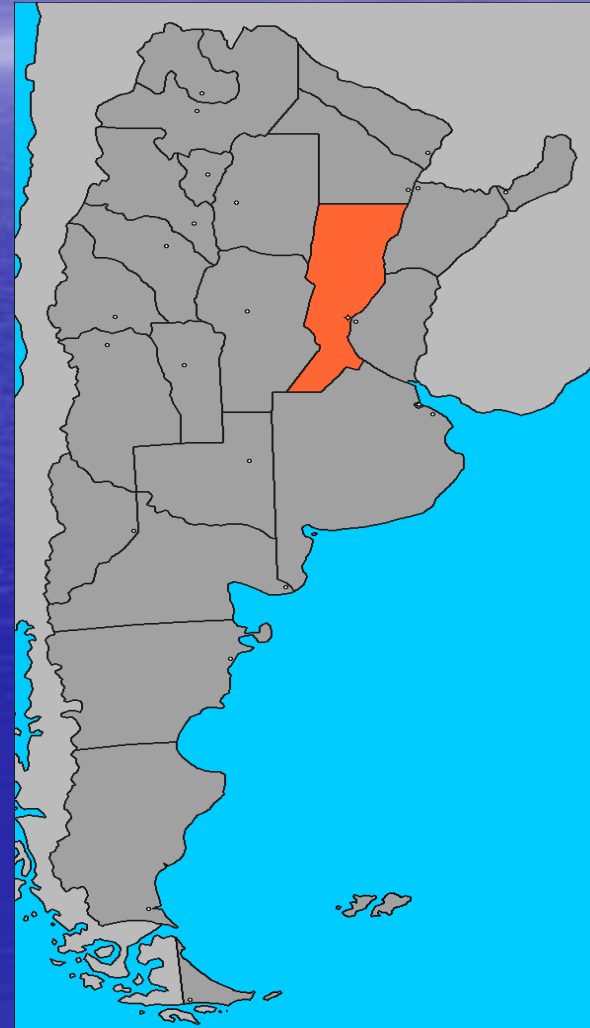
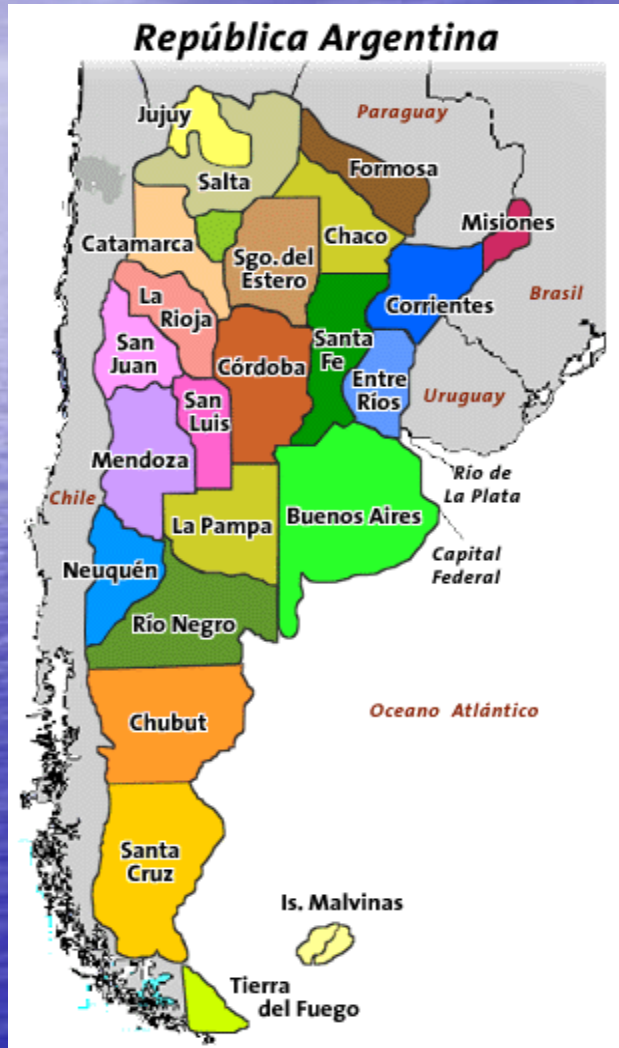
- 2009- Entre Ríos (Argentina) (At the beginning producing data of the city of Concordia: CIV 8th ed) is facing now economic restrictions due to the present crisis: the subsidy given by the Province was stopped and Dr. Miguel Prince expressed his preoccupation for that (April 8, 2009): amount u\$s 1000/year.



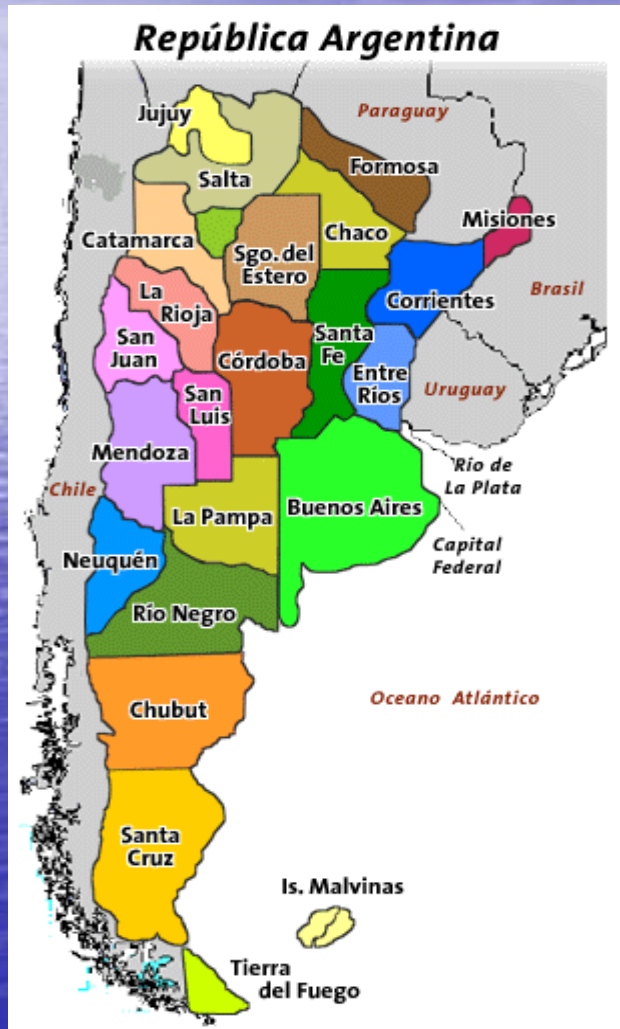
Both cases can make us reflect about the importance of IARC seed grants.....

Other problems expressed by the Registries are: lack of professional staff, for example:

- Santa Fe Cancer Registry (Argentina): they are 4 persons provided by the Province including an informatic . They need the profesional level.



•Rio Negro Province Cancer Registry (Argentina): They lack professional direction for an year and a half (argument between the Cancer Registry Director and the Health Minister.....





# **III - SOME CONCLUSIONS AND PROPOSALS**

- 1) The International Associations and Agencies like WHO, IARC, IACR, UICC, could elaborate a consensus to advise the health authorities of South America and probably of other continents how to secure the continuity of the Cancer Registries in order that in large countries good quality cancer data be achieved representing different regions of each country.

This consensus could be called Framework Consensus on Cancer Registration or Framework Consensus on Cancer Control.

# **SOME CONCLUSIONS AND PROPOSALS**

2) This Consensus could be the first step to reach a Framework Convention on Cancer Registration and Cancer Control that could be historically the second global agreement among all countries in the world to achieve a global success, being the first one the FCTOH.

3) The signing countries would compromise at the local level to passing a National Cancer Law Regarding Cancer Registration and Cancer Control. The 1971 Cancer Law in the US, is probably an historical landmark regarding this issue.

# **SOME CONCLUSIONS AND PROPOSALS**

- 4) The regions selection in each country should be defined by epidemiological criterion like cancer mortality, feasibility and local leadership.
- 5) The cancer Registration area should have ideally between 500.000 and 1.500.000 inhabitants avoiding the excessive expense and complexity of more populated areas and the low representative data of very little places.

## **SOME CONCLUSIONS AND PROPOSALS**

- 6) The continuity of the Registries should be guaranteed as the stability of its personnel.
- 7) A Central Unit, Office, Service or Institute should exist in each country with capacity to analyze the cancer data and at the same time supervise its quality. It could probably be able to make recommendations at the National and Provincial levels about Cancer Control.
- 8) Eventually an Office or Delegation of International Agencies could be created in each continent to stimulate, give continuity and evaluate these strategies.

The background of the image is a photograph of a vast blue ocean meeting a bright blue sky with wispy white clouds. The text is centered and written in a bold, orange, rounded font with a black outline.

Thank you very  
much for your  
Attention!