UICC Members Regional Meeting – Latin America and the Caribbean
Agenda

- Introduction
- Presentation of 3 collaborations – case studies
- How can UICC support
- Discussion
- Conclusion
CASE STUDIES
ULACCAM
ASAPRECAN-FEMAMA-TÓMATELO A PECHO

Case study

PARLIAMENTARY FORUM ON WOMEN’S CANCER: ADVOCACY IN ACTION ON LATIN AMERICA.

DR. LISSETH RUIZ DE CAMPOS
ASOCIACION SALVADOREÑA PARA LA PREVENCIÓN DEL CÁNCER
UICC - ULACCAM
Summary

Each year, in Latin America, approximately 36,952 women with breast cancer die and 31,712 women with cervical cancer die. The governments of our region need to be better prepared to face the impact that women’s cancer has on the economy, the family and society.

To promote legislation and effective public policies in the region, in relation to the cancers of women, the Latin American Union against Cancer for Women was formed.

Based on successful experiences of legislative advocacy in Brazil, El Salvador and Mexico, we decided to create a collaborative initiative that will allow us to strengthen the capacities of our partner organizations and other non-member organizations in the region, in legislative advocacy, as well as promote legislation and policies public reports on women’s cancers.
OBJECTIVES

•GLOBAL OBJECTIVE: Contribute to reduce the incidence of cancers in women and the number of deaths from this cause in Central America, through education and legislative advocacy before Women's Parliamentary Groups.

SPECIFIC OBJECTIVES:

1. Improve the knowledge of women parliamentarians and civil society delegates regarding the cancers of women and their epidemiology in Central America.

2. Promote the strengthening of Central American legislation related to the Prevention and Control of Cancer in Women, through advocacy.

3. Promote the exchange of experiences among various regional organizations focused on the fight against women's cancer and women's parliamentary groups.

4. Promote a monitoring and surveillance system about public policies and regional legislation on women's cancers.
The Advocacy Workshop and the Forum with the Parliamentarians have the capacity to be replicated in different countries of the Region and the world, due to:

- In all the countries of the region, there are civil society organizations that are members of the UICC or of other coalitions, which would benefit from strengthening their capacities in advocacy.
- The programmatic content of the workshop is available, which guarantees that it can be reproduced without major modifications.
- The first forum will serve as a pilot proof; its effectiveness will be evaluated through the pre and post workshop survey.
- There is a coordination team that can be moved to the countries where it is wanted to be implemented, which ensures an adequate transfer of knowledge.
- In all the countries of the region there are parliamentarians women, and there are different organizations that group them.
Engagement opportunities

COUNTRIES:

Second Stage (2019): Argentina, Brazil, Colombia, Ecuador, Peru, Uruguay, Venezuela, Bolivia, Paraguay, Chile.
Case study

**Cancer Navigator:**
A RESOURCE TOOLKIT FOR CANCER PATIENTS AND CAREGIVERS

**Global Focus on Cancer**
Carolyn Taylor, Global Focus on Cancer
Dr. Carlos Castro, La Liga Colombiana Contra el Cáncer
Dr. Tran Thanh Huong, Bright Future Foundation

**Colombia:**
- La Liga Colombiana Contra el Cáncer
- Instituto Nacional de Cancerología
- Hospital Universitario San Ignacio
- Fundacion Simmon
- Ministerio de Salud y Protección Social
- Tom Laffay Film - video

**Vietnam:**
- Bright Future Foundation
- National Cancer Hospital K3
- Ho Chi Minh City Oncology
- Can Tho Oncology Hospital
- Hanoi Medical University
- Vietnam Cancer Society
- Noi Pictures - video
Challenge and Solution: Cancer Navigator

Challenge:

- LIMITED ONCOLOGY RESOURCES
- HEALTH LITERACY GAP
- LACK OF SUPPORT SERVICES

Solution:

- Informational support
  - Infographic and personal narrative videos
  - Cancer basics/Cancer 101
  - Treatment options/side effects
  - Necessary precautions, hygiene, nutrition
- Navigational support
  - Locally available and affordable
    - Housing
    - Food
    - Transportation
- Delivery methods
  - TV/video monitors, stand alone kiosks, tablets
  - Linked to hospital/country web/social media
  - Stand alone YouTube channel
  - Printed materials
**Goals/outcomes:**

- Fill gaps in education, navigation and awareness
- Provide practical information specific to cancer & its treatment
- Encourage patient compliance
- Provide knowledge & resources to positively effect patient outcome
- Ease the burden on hospital staff
- Reduce patient distress
- Improved quality of life for patients

**M & E:**

- Quarterly conference/skype calls
- Semi-annual sites visits
- Convene stakeholders & beneficiaries
- On-line surveys
- In person interviews
- Present results at various professional conferences
- Publish results in relevant academic journals
Lessons learned

• If we could change one thing, we would consider hiring a local public health professional in each country for on-site overseeing of the program throughout the duration of the project.

• The most significant challenges were:
  • The strain put upon local partners who are already struggling with a lack of manpower and resources in order to assess and evaluate patient needs for building the narrative for the videos scripts.
  • The difficulties associated with not having a dedicated representative on-site in each country.

• What has worked particularly well is that all the parties involved have been extremely enthusiastic regarding the potential of the program in addressing the needs of and offering solutions for cancer patients and their caregivers while relieving the burden on the hospital staff.
Engagement opportunities

- At this point, due to funding restrictions, this is a closed initiative.
- Once the respective videos have been produced and introduced in each of the partner countries, we will be happy to share them with additional oncology sites within Colombia and Vietnam, providing the content is both resource and culturally appropriate for the new location. We are also happy to consult with anyone interested on how we designed and implemented the program.

To learn more, please contact Carolyn Taylor, Founder/President of Global Focus on Cancer at: carolyn@globalfocusoncancer.org
Other organisations or stakeholders involved:
100 organizations - Government, patient advocacy organizations, oncologists, medical societies, media, layers, companies, Hospitals, Cancer centers, Physicians, Health professionals
Summary

- Brazil published in 2013 (Law 874 – 2013) a national law that regulates the prevention and control of Cancer in the country, but the law is not fulfilled in its entirety.
- The Movement All Together Against Cancer was created to monitor and enforce this Law- cancer prevention and control.
- Cancer is a very complex subject and there are many stakeholders involved, so the collaboration of all is essential to achieve the society and government engagement.
- The Movement consists of 18 working groups, aligned with the dynamics of treatment in Brazil, which seek to assure the law 874-2013 implementation, in all its guidelines.
- The working groups are multidisciplinary, with diverse stakeholders, bringing broad knowledge to generate the necessary changes.
- Once a year the All Together Against Cancer Congress takes place, where all topics related to the Cancer in Brazil are discussed, and serve as an engine for the work groups continue with their work.
Results achieved (or expected)

• The Movement seeks the fulfillment of the law in its entirety by the health authorities, with effective actions, to guarantee the best prevention, diagnosis and treatment for cancer patients.

• Two important programs are already under implementation: Onco teaching (online education) and Observatory of Oncology – Open data por social transformation

  • Onco teaching
    • 10,000 professionals attended classes until June, 2018 (since Oct 2016 when program started)
    • 140 public treatment centers of the Unified Health System (SUS) offering the tool to their team
    • 250 top Brazilian oncology specialists involved in content development
    • Nationwide scope - 24 of the 27 Brazilian States.

  • The Oncology Observatory is an online and dynamic platform for monitoring open data and sharing relevant information from the oncology area of Brazil.
    • Open data bases as source of information
    • More than 50 published studies
Lessons learned

• The creation of a unique agenda gives focus and strength to our requests to the government
• On the other hand many people are still not prepared to work as a team
• It is very important that the associations involved can bring their projects to gain strength if they wish so
• Maintain the goal to enforce the law 874-2013, does not let us lose focus

Suggestion:
• Where there is no law focused on Cancer, establish clear priorities for action, write and follow these priorities to avoid losing focus.
• In parallel, with these priorities in hand, find a good-will Politician who writes the law and can help to approve it.
• When we have the law in our favor, things get easier
Engagement opportunities

• This initiative will continue until we reach our goals
• We are still engaging people, and when government changes (2019) we need to include many new stakeholders
• For now we only operate in Brazil, but who knows in the future we can have a Latin American initiative
Opportunities for UICC Members

Connect globally

- CEO PROGRAMME
  Leadership in Action meetings
  5 regions in 2019
  Short term Leadership Grants

- YOUNG LEADERS
  April 2019 Call for Applications

Leadership Development

Grants and Fellowships

- GRANTMAKING OPPORTUNITIES FOR ORGANISATIONS:
  SPARC Metastatic breast cancer
  Expansion to other topics in 2019

- FELLOWSHIPS FUNDING
  1-month learning visit for all professionals – All year long

Treatment for All: National activation

- CHAMPION A NATIONAL TFA INITIATIVE
  October 2018: Call for expressions of interest launched
  Support country needs assessment
  Launch dedicated Toolkit on WCD
  Mentoring from experts

Regional engagement

Adapting, facilitating access to & developing activities aligned with Members’ needs and UICC priorities
Discussion

Suggested questions to discuss:

• What would you like to see from UICC?
• What are the needs from the region that would benefit from a collaborative response?
• Who are the stakeholders to have onboard to ensure impact in collaborations?
• Are there inputs/experiences you would like to share with your peers?
Thank you!

Contact us at:
- membership@uicc.org
- regionalcb@uicc.org

worldcancercongress.org