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# ORGANIZING COMMISSION

#### SCIENTIFIC COORDINATION

Beatriz de Camargo | Researcher at the Research Center in the Technological Development and Clinical Research Division – National Cancer Institute of Brazil

#### TECHNICAL COORDINATION (Instituto Desiderata)

Roberta Costa Marques | Executive Director Laurenice Pires | Health Manager

#### **COMMISSION MEMBERS**

#### Fundação do Câncer Hospital

Alfredo Scaff | Medical Consultant Jaqueline Almeida | Fundraising Analyst

#### Jesus Municipal Hospital

Ariane Molinaro | Director Débora Angeli | Medical Director

#### Instituto Desiderata

Carolina S. Motta | Health Analyst
Claudia Bezerra | Project Coordinator
Evelyn K. dos Santos | Health Analyst
Fábia Andérez | Communications Manager
Luiza Rudge | Manager of Institutional Development

#### National Cancer Institute (INCA)

Marceli de O. Santos | Technologist in the Situation Monitoring and Analysis Division Nathalia Grigorovski | Pediatric Oncologist Sima Ferman | Head of Pediatric Services

# Instituto de Pediatria e Puericultura Martagão Gesteira (IPPMG/UFRJ)

Elaine Sobral | Pediatric Oncologist and Adjunct Professor of the College of Medicine

#### Municipal Health Secretariat (SMS-Rio)

Ana Lucia Reis Mello | Program Manager for Cancer Control Carlos Ornelas | Technical Assistant of Cancer Control Program Flávia Barcelos | Technical Assistant for Children's Health

#### State Department of Health (SES-RJ)

Ana Caroline Medina | Primary Care Managing Technician Carmem Sampaio | Primary Care Managing Technician

#### Rio de Janeiro State Pediatric Society (SOPERJ)

Áurea Grippa | Director of Courses and Events



CHILDHOOD CANCER REPRESENTS THE LEADING CAUSE OF DEATH BY DISEASE IN BRAZIL, where there are an estimated 12,500 new cases every year in a country which faces enormous regional disparities and below-average survival rates. The Pediatric Oncology Forum (POF) arose as a space for debate to confront these challenge and, above all, to elaborate proposals which contribute to improving the healthcare network for children and adolescents with cancer.

The POF is collectively constructed every year and was conceived by United for a Cure, a program which promotes early diagnosis so as to organize the flux of children who require cancer screening in the city of Rio de Janeiro. It has already trained over 4-thousand of the state's professionals to detect early signs of cancer. This has allowed for 90% of these children to schedule an appointment within 72 hours of their primary care visit and be sent to a qualified care center for diagnosis.

In this fifth edition, themes which are relevant to the implementation of public policy were addressed over three days of speeches, courses, and work groups, which recommended actions necessary to the advancement of public policies in pediatric oncology, cancer registries, and subjects regarding Rio de Janeiro and various other regions in the country.

Its national relevance became even more clear in 2019 with the meeting of the Global Initiative for Childhood Cancer, an initiative launched by the World Health Organization and whose objective is to increase the survival rate to 60% in all the world's countries. This global priority strengthens local actions and reveals an area of convergence in relation to childhood cancer, a complex disease which is tangibly benefitted by uniting forces between national and international pediatric oncologists, public administrators, and civil society.

Some recent advancements have been achieved in pediatric oncology-related public policy: we began a pilot project for implanting the Toronto Consensus, standardizing the

staging system for pediatric tumors in registries; we included a path for sending pediatric cancer screenings to the state regulatory system, formalizing a fast track for cancer screening in all of Rio de Janeiro; and we advanced in humanizing child care services, supporting the palliative care teams in specialized hospitals.

However, there is still much to be done: publish and monitor a plan for oncological attendance, implement the population-based cancer registry (PBCR) in the city of Rio de Janeiro, still inexistent at a state level, guarantee the training of pediatric palliative care teams, and increase training across the state in order to organize reference flows, among other objectives.

We created this report which brings together debates and referrals from the 5th Rio de Janeiro Pediatric Oncology Forum, highlighting advancements and joint action which is necessary for increasing our chances at curing childhood cancer. We hope that public administrators, health professionals, and social organizations reaffirm their commitment to the cause and prioritize strategic actions which can transform the reality of children and adolescents with cancer.

#### **Roberta Costa Marques**

Technical Coordinator of the 5th Rio de Janeiro Pediatric Oncology Forum Executive Director, Instituto Desiderata

#### **Beatriz de Camargo**

Scientific Coordinator of the 5th Rio de Janeiro Pediatric Oncology Forum Researcher at the National Cancer Institute





#### 5<sup>™</sup> PEDIATRIC ONCOLOGY FORUM

The Pediatric Oncology Forum is a space for debating and elaborating proposals which contribute to improving the healthcare network for children and adolescents with cancer. In this fifth edition, themes which are pertinent to the implementation of public policy were addressed over three days of speeches, courses, and work groups which recommended actions regarding the advancement of public policy in pediatric oncology. Subjects included: early and accurate diagnoses, access to treatment, professional training, pediatric palliative care, cancer registries, and various subjects relevant to Rio de Janeiro and other regions around the country.

The opening conference was held by Dr. Carlos Rodriguez Galindo, pediatric oncologist and director of St. Jude Global. He presented an overview of childhood cancer around the globe. With modern therapies, it is now possible to achieve survival rates of over 80% among children and adolescents with cancer. However, as more than 80% of children diagnosed with cancer live in countries with limited resources, the global survival rate of the disease is far lower than desired.

One of the highlights of the 5th Pediatric Oncology Forum was the presentation of the Global Initiative for Childhood Cancer, launched by the World Health Organization and whose objective is to reach at least a 60% survival rate for children with cancer by 2030, thereby reducing the disparities which currently exist in the world. The meeting, which included the presence of Dr. Carlos Rodriguez Galindo and 40 other national and international leaders in the area, produced a Letter of Recommendations which was sent to the Ministry of Health, soliciting Brazil's participation in the Initiative. This global priority strengthens local actions and reveals another area of convergence regarding childhood cancer, a complex disease which tangibly benefits from uniting forces between national and international pediatric oncologists, public administrators, and civil society.

The scientific event presented 8 hours of exclusive content and 21 speeches which outlined the general scenario, successful experiences, as well as the challenges faced by the healthcare network for children and adolescents with cancer. Significant advancements have been achieved, such as the promotion of early diagnosis in Rio de Janeiro city, the increase in treatment centers, the construction and maintenance of support centers for non-governmental organizations and social support for families. However, in order to increase the survival rate, it is still important to advance in certain, extremely important areas. Reducing inequalities in treatment between regions in Brazil, the institutions' low adherence to standard protocols, patients being attended outside of specialized centers, payments to centers which do not fulfill the minimum conditions required by the SUS public health system, the lack of inspections as well as medication are a few examples of challenges that are still to be overcome. It is essential that the three spheres of government recognize childhood cancer as a healthcare priority and act together to alter the current reality.

An essential factor in strengthening public policy regarding pediatric oncology is health-related information. Population-based cancer registries create a data set which is fundamental to understanding the reality of pediatric oncology in the country. Cancer incidence and survival rates are two examples which should help guide public policies geared toward access to quality treatment. This would contribute to greater survival rates for children and adolescents. The discussions raised in the POF led to a consensus that a fully-functioning registry with standardized information on tumor staging represents an essential tool for planning any treatment program and for controlling pediatric cancer.

Palliative care has progressively gained space in discussions regarding public policy, especially at the international level. In Brazil, although a specific national policy does not exist, in 2018, guidelines for the organization of integrated, continued palliative care in SUS were published. According to data from the Brazilian National Academy of Palliative Care, 177 registered teams exist, 37 of which are specialized in pediatric palliative care. In the city of Rio de Janeiro, municipal hospitals carried out important training initiatives over the last few years; at the state level, mobilization by civil society culminated in the approval of a law which created the State Palliative Care Program. Speakers guaranteed that these latest advancements were significant, but that a few challenges still must be overcome; for example, the approval of a national public policy regarding palliative care which specifically addresses pediatric care, and the effective implementations of the policy at different levels of the SUS system.

#### 5<sup>TH</sup> PEDIATRIC ONCOLOGY FORUM

Latin American experiences tend to share this coordination between governments, hospitals, and non-governmental organizations, as well the use of consistent information in guiding the planning and integration between different levels of attendance. The challenges imposed by childhood cancer are complex and depend not only on the joint action of municipal, state, and federal government, but also on the active participation of academic and social organizations.

Innovative actions in care and administration shed a light on new opportunities for improving the public network: the development of an application to facilitate communication with specialists and the early diagnosis of childhood cancer; cancer education for younger patients; a project for preventing treatment abandonment; and an initiative for coordination and collective planning which involves all the actors in a city. Many experiences inspired the discussion and uncovered different paths.

The work groups delved into the following themes: early, accurate access to treatment, professional training, pediatric palliative care, and cancer registries. This all culminated the elaboration of a Letter of Recommendations which was sent to state and municipal administrators, hospitals, and representatives of civil society.

In summary, some recent advancements have been achieved regarding pediatric oncology and public policy, such as the pilot project for implementing the Toronto Consensus, standardizing the staging of pediatric tumors for use in the registry; the inclusion of a path for sending pediatric cancer screenings to the state regulatory system, formalizing a fast track for cancer screenings through Rio de Janeiro state; and improving the humanization of services which attend children, including supportive action for palliative care teams in specialized hospitals.

However, there is still much to be done: publish and monitor a plan for attending oncology patients, implement a population-based cancer registry (PBCR) in Rio de Janeiro city (still lacking at the state level), guarantee the training of pediatric palliative care teams, and increase training throughout the state in order to organize reference flows, among other objectives.

We created this report which brings together debates and referrals from the 5th Rio de Janeiro Pediatric Oncology Forum, highlighting advancements and joint action which is necessary for increasing our chances at curing childhood cancer. We hope that publics administrators, health professionals, and social organizations reaffirm their commitment to the cause and prioritize strategic actions which can transform the reality of children and adolescents with cancer.



### **NUMBERS 2019**



A LETTER with recommendations for improving the healthcare network

225 participants in three days



3 DAYS of activities in Rio de Janeiro



# 15 THEMES

specifically addressed in work groups, presentations, courses, workshops and meetings

# **SPEAKERS**



INTERNATIONALS 54 NATIONALS

# **PROMOTIONAL VIDEO**

Watch the video of the 5th Pediatric Oncology Forum: http://foprio.org.br/fop-5/



## **OPENING**

#### MEETING ON THE GLOBAL CHIDHOOD CANCER INITIATIVE

DATE: 09/30 LOCATION: FIRJAN (Av. Graça Aranha, 1 / 3<sup>rd</sup> floor – Centro)



One of the highlights of the 5th Pediatric Oncology Forum was the presentation of the Global Childhood Cancer Initiative, launched by the World Health Organization at the 2018 UN General Assembly. The initiative seeks to achieve at least a 60% survival rate among children and adolescents with cancer by 2030, thereby reducing the survival rate disparities which exist around the world. The meeting, which included Dr. Carlos Rodriguez Galindo and 40 other national and international leaders in the area, allowed for a debate on the Brazilian context and potential opportunities which prioritize childhood cancer patients in the Sistema Unico de Saude (SUS). This debate resulted in a Letter of Recommendations which asked for Brazil's participation in the Initiative and was sent to the Ministry of Health.

#### **OPENING NIGHT**

DATE: 09/30 LOCATION: FIRJAN (Av. Graça Aranha, 1 / 3<sup>rd</sup> floor – Centro)



The opening conference, which provided an overview of childhood cancer across the globe, was led by Dr. Carlos Rodriguez Galindo, pediatric oncologist and director of St. Jude Global. With modern therapies, it is now possible to reach survival rates of over 80% among children and adolescents with cancer. However, as more than 80% of children diagnosed with cancer live in countries with limited resources, the global survival rate of the disease is far lower than desired. At the conference, various global initiatives were presented which seek to change the international situation and which are being led by St. Jude Global and the World Health Organization.

The opening included a presentation by the UFRJ saxophone group and the Musica nas Escolas project, a musical development program geared toward students from the Barra Mansa public school network. The opening roundtable discussion included representatives from Instituto Desiderata, the Brazilian Society of Pediatric Oncology, the Ministry of Health, the State Department of Health, and the Rio de Janeiro Municipal Health Secretariat.

# **SCIENTIFIC EVENT**

DATE: 10/01 LOCATION: FIRJAN (Av. Graça Aranha, 1 / 2<sup>nd</sup> floor – Centro)

#### NUMBERS FROM THE SCIENTIFIC EVENT

8 hours
of exclusive content





- Overview of childhood cancer in Brazil
- ✓ Latin American experiences in pediatric oncology
- ✓ Population-based cancer registries
- Innovations in care, public administration, and approaches to facing cancer
- Pediatric palliative care in Brazil



# TABLE 1: OVERVIEW OF CANCER IN CHILDREN AND ADOLESCENTS: WHERE ARE WE NOW AND HOW DO WE MOVE FORWARD?

#### **SPEAKERS**

Ana Cristina Pinho Mendes Pereira | National Cancer Institute and Ministry of Health, Brazil

landara Moura | State Department of Health, Rio de Janeiro

Paulo Peres | Municipal Health Secretariat, Rio de Janeiro

Cláudio Galvão de Castro Jr. | Brazilian Society of Pediatric Oncology, Brazil

#### **MEDIATOR**

Roberta Costa Marques | Instituto Desiderata, Rio de Janeiro



#### **SUMMARY**

Discussion about the current state of pediatric oncology, including the advances and challenges observed over the last few years and what actions are necessary for raising the level of care. Significant advancements were achieved, such as the successful experience of United for a Cure in Rio de Janeiro city as well as other effective early diagnosis programs around the country, the increase in treatment centers, the construction and maintenance of support centers for non-governmental organizations and social support for families. However, it is still important to achieve extremely relevant goals in order to increase survival rates. Reducing inequalities in treatment between regions in Brazil, the institutions' low adherence to standard protocols, patients being attended outside of specialized centers, payments to centers which do not fulfill the minimum conditions required by the SUS public health system, and the lack of inspections as well as medication are a few examples of challenges that are still to be overcome. It is essential that the three spheres of government recognize childhood cancer as a healthcare priority and act together to alter the current reality.



THE FORUM

# TABLE 2: PEDIATRIC ONCOLOGY HEALTHCARE NETWORKS: LATIN AMERICAN EXPERIENCES

#### **SPEAKERS**

How can we maintain public policies which guarantee care for children and adolescents with cancer from different backgrounds? – Carlos Rodriguez Galindo| Hospital St. Jude, Memphis, EUA

Overview of the National Pediatric Cancer Plan in Peru – Liliana Vasquez | Ministry of Health, Peru

Pediatric National Cancer Program in Chile: the experience of PINDA - Milena Villarroel | PINDA, Chile

United for a Cure: the experience of early diagnosis in childhood cancer in Rio de Janeiro – Laurenice Pires | Instituto Desiderata, Rio de Janeiro, Brazil

#### **MEDIATOR**

Isis Magalhães | Hospital da Criança, Brasilia, Brazil



#### **SUMMARY**

This discussion presents Latin American countries' successful experiences in implementing pediatric oncology healthcare networks in order to increase survival rates, guaranteeing a more equitable level of care for these patients. These experiences all share the challenge of coordinating between governments, hospitals, and non-governmental organizations, as well the use of consistent information in guiding the planning and integration between different levels of care. The challenges imposed by childhood cancer are complex and depend not only on the joint action of municipal, state, and federal government, but also on the active participation of academic and social organizations. The speakers emphasized that, in order to achieve better results, it is important that all of these actors are involved in collaborative, interdisciplinary, and network-based work.



THE FORUM

#### TABLE 3: THE IMPORTANCE OF POPULATION-BASED CANCER REGISTRIES

#### **SPEAKER**

How can the standardization of pediatric cancer registries define the elaboration and planning of public policies geared toward access to quality treatment and contribute to greater survival rates? – Gemma Gatta | Fondazione IRCCS National Cancer Institute, Italy

The Evolution of Population-based Cancer Registries in Brazil - Marceli de Oliveira

Santos | National Cancer Institute and Ministry of Health, Brazil

The participation of Population-based Cancer Registries in global research and projects: the PBCR experience in Aracaju – Carlos Anselmo Lima | State Health Department, Sergipe, Brazil

#### **MEDIATOR**

Beatriz de Camargo | National Cancer Institute and Ministry of Health, Brazil



#### **SUMMARY**

Population-based cancer registries create a data set which is fundamental to understanding the reality of pediatric oncology in the country. Cancer incidence and survival rates are two examples which should help guide public policies geared toward access to quality treatment. This could contribute to greater survival rates for children and adolescents. Currently, Brazil has 33 population-based cancer registries, 1 of which is inactive (Rio de Janeiro) and 28 of which include accessible information. The discussions raised in the POF led to a consensus that a fully-functioning registry with standardized information on tumor staging represents an essential tool for planning any treatment program and for controlling pediatric cancer.



THE FORUM

# TABLE 4: INNOVATIONS IN PEDIATRIC ONCOLOGY: EXPERIENCES WITH INNOVATIVE ADVANCEMENTS IN CARE, PUBLIC ADMINISTRATION, AND APPROACHES TO FACING CANCER

#### **SPEAKERS**

ONCO-PEDS: an application for early diagnosis and referrals in childhood cancer – Liliana Vasquez | Ministry of Health, Peru

Let's talk about cancer? How to teach children about the Incredible Cellular Universe – Luciana Lobo

| Instituto ZENCancer, Rio de Janeiro, Brazil

Cancer: a global problem with local solutions – the engagement process from the cities of the City Cancer Challenge – Stephanie Shahini | City Cancer Challenge, Porto Alegre, Brazil

Strategies for preventing treatment abandonment in children with cancer – Sima Ferman |

National Cancer Institute and Ministry of Health, Brazil

#### **MEDIATOR**

Marcelo Land | Instituto de Puericultura e Pediatria Martagão Gesteira (UFRJ), Rio de Janeiro, Brazil



#### **SUMMARY**

This roundtable discussion showed the experiences regarding innovative actions and care and administration while facing cancer. Liliana Vasquez presented a Peruvian application used for facilitating communication with specialists, thereby improving early diagnosis in childhood cancer cases. Through the tool, generalist healthcare professionals were able to field questions with specialists and make referrals more easily in suspected cases of childhood cancer. Luciana Lobo presented the Incredible Cellular Universe, a project which seeks to teach children under treatment about the cellular universe. Through "storytelling" workshops, the children learn about the innate and adaptive immune systems, chemotherapy, and emotions' influence on cells. Stephanie Shahini explained her experience in Porto Alegre, one of the participant cities in the City Cancer Challenge, a global project for planning and collective action related to cancer. The idea is to unite forces and identify problems while thinking of solutions which alter the current reality. To close, Sima Ferma presented a project for preventing treatment abandonment in children with cancer in INCA. The project reduced this rate by 63.8% between 2013 and 2017. Risk factors for treatment abandonment were identified and the patients' families received personalized strategies aimed toward their particular difficulties.



#### TABLE 5: PEDIATRIC PALLIATIVE CARE IN BRAZIL: WHERE ARE WE NOW?

#### **SPEAKERS**

Palliative care in public policy: from regulation to implementation – Neulânio Francisco de Oliveira | Materno Infantil Hospital, Brasilia, Brazil

Overview of current pediatric palliative care in Rio de Janeiro –

Débora Mattos | National Cancer Institute and Ministry of Health, Brazil

Palliative care and civil society: mobilization and advocacy -

Ana Paula Menezes Bragança dos Santos | National School of Public Health (FIOCRUZ), Brazil

#### **MEDIATOR**

Ernani Costa Mendes | National School of Public Health (FIOCRUZ), Brazil



#### **SUMMARY**

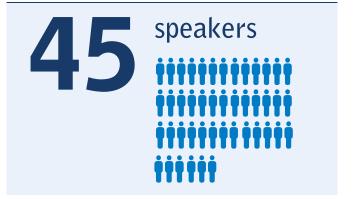
Over the last few years, palliative care has progressively gained space in public policy discussions, especially at the international level. In Brazil, although a specific national policy does not exist, in 2018, guidelines for the organization of integrated, continued palliative care in SUS were published. According to data from the Brazilian National Academy of Palliative Care, there are 177 registered teams, 37 of which are specialized in pediatric palliative care. In the city of Rio de Janeiro, municipal hospitals have carried out important training initiatives over the last few years; at the state level, mobilization by civil society culminated in the approval of a law which created the State Palliative Care Program. Speakers guaranteed that these latest advancements were significant, but that a few challenges still must be overcome; for example, the approval of a national public policy regarding palliative care which specifically addresses pediatric care, and the effective implementation of the policy at different levels of the SUS system.



# **COURSES, WORKSHOPS, AND MEETINGS**

## **NUMBERS, COURSES AND MEETINGS**

30 hours of exclusive content

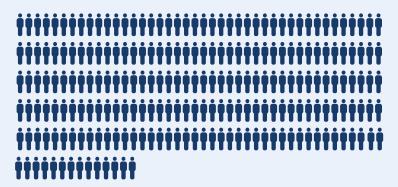




- Pediatric oncology with a focus on the Multi-professional Primary Care Team
- Retinoblastomas
- ✓ Pediatric palliative care
- **✓** Standardized staging in childhood cancer
- Social rights and pediatric oncology
- ✓ Gaining supporters for childhood cancer

174

participants



# PEDIATRIC ONCOLOGY WITH A FOCUS ON THE MULTI-PROFESSIONAL PRIMARY CARE TEAM

DATE: 10/02 MORNING

LOCATION: FIRJAN (Av. Graça Aranha, 1 / 3rd floor – Centro)

#### COORDINATION

Jorge Monteiro | National Cancer Institute and Ministry of Health, Brazil Sima Ferman | National Cancer Institute and Ministry of Health, Brazil

#### **SPEAKERS**

Ana Paula Daltro Leal de Paiva | Municipal Health Secretariat, Rio de Janeiro, Brazil

Arissa Ikeda | National Cancer Institute and Ministry of Health, Brazil

Clarice Gerbassi | State Department of Health, Rio de Janeiro, Brazil

Daniela Leite | HEMORIO and State Department of Health, Rio de Janeiro, Brazil

Gabriela Oingman Bellas | National Cancer Institute and Ministry of Health, Brazil

Jorge Leandro de Souto Monteiro | National Cancer Institute and Ministry of Health, Brazil

Larissa Uemoto | National Cancer Institute and Ministry of Health, Brazil

Licia Neves Portella | National Cancer Institute and Ministry of Health, Brazil

Marilia Fornaciari Grabois | National Cancer Institute and Ministry of Health, Brazil

Sima Ferman | National Cancer Institute and Ministry of Health, Brazil

Senir Santos da Hora | National Cancer Institute and Ministry of Health, Brazil



#### **SUMMARY**

It is estimated that 40% of childhood cancer diagnoses are made when the tumors have already developed. This occurs mainly because the symptoms are confused with common childhood diseases, as well as due to children's difficulties in communicating and the relative rarity of the disease. Therefore, investing in early diagnosis is essential. This course takes a multidisciplinary focus to epidemiology, the signs and symptoms of childhood cancer, and oncological emergencies in basic care, among other subjects. The main theme was the multi-professional approach to caring for the child and their family regarding problems caused by the disease, such as accompanying the family beyond therapy and reinserting the patient and their family into the community.



#### **RETINOBLASTOMA MEETING**

DATE: 10/02 MORNING

LOCATION: FIRJAN (Av. Graça Aranha, 1 / 4th floor – Centro)

#### COORDINATION

Clarissa Campolino de Sá Mattosinho | National Cancer Institute and Ministry of Health, Brazil Nathalia Grigorovski | National Cancer Institute and Ministry of Health, Brazil

#### **SPEAKERS**

Célia Antoneli | Nove de Julho University, Sao Paulo, Brazil

Clarissa Campolina de Sá Mattosinho | National Cancer Institute and Ministry of Health, Brazil

Guillermo Chantada | Latin American Soceity of Pediatric Oncology, Argentina

Karina de Cássia Braga Ribeiro | Faculty of Medical Sciences of Santa Casa, Sao Paulo, Brazil

Leila Leontina Couto | National Cancer Institute and Ministry of Health, Brazil

Nathalia Grigorovski | National Cancer Institute and Ministry of Health, Brazil



#### **SUMMARY**

By presenting a clinical case, the course discussed the construction of a line of care for retinoblastoma in Brazil. The meeting was an opportunity to reflect on possible actions and services to be developed in different points of the healthcare network which would consider the realities of the different locations. The main points which were debated included: how to keep children from showing up at the care centers with an already advanced stage of the disease? What variables are responsible for the decreased levels of survival and preservation of eyesight? In what ways can we intervene?



#### PEDIATRIC PALLIATIVE CARE: A REALITY UNDER CONSTRUCTION

DATE: 10/02 MORNING

**LOCATION:** FIRJAN (Av. Graça Aranha, 1 / 4<sup>th</sup> floor – Centro)

#### COORDINATION

Ana Paula Menezes Bragança dos Santos | National School of Public Health (FIOCRUZ), Brazil

Débora Mattos | National Cancer Institute and Ministry of Health, Brazil

Ernani Mendes | National School of Public Health (FIOCRUZ), Brazil

Laurenice Pires | Instituto Desiderata, Rio de Janeiro, Brazil

#### **SPEAKERS**

Débora Mattos | National Cancer Institute and Ministry of Health

Ernani Costa Mendes | National School of Public Health (FIOCRUZ), Brazil

Edna Moreira | Hospital Universitário Gaffrée e Guinle (UNIRIO), Rio de Janeiro, Brazil

Ana Paula Menezes Bragança dos Santos | National School of Public Health (FIOCRUZ), Brazil

Bruno Oliveira | National Cancer Institute and Ministry of Health, Brazil

Luciana Ramalho | Hospital Estadual da Criança, Rio de Janeiro, Brazil

#### **MEDIATOR**

Érica Tavares Quintans | Instituto Desiderata, Rio de Janeiro, Brazil



#### **SUMMARY**

Palliative care is an approach which seeks to improve the quality of life of the patients and families facing life-threatening diseases through the prevention and relief of suffering, early identification, first-rate assessment, and through the treatment of pain and other physical, psychosocial, and spiritual issues (WHO, 2017). This course presented general palliative care concepts, principles, the importance of working together with other teams, and the challenges for implementation in Brazil; the concepts of communicating difficult information, specifically related to children, the role of spirituality in palliative care, and the importance of indicators for measuring results and qualifying practices in this area.



#### STANDARDIZED STAGING IN CHILDHOOD CANCER

DATE: 10/02 MORNING

**LOCATION:** FIRJAN (Av. Graça Aranha, 1 / 4<sup>th</sup> floor – Centro)

#### COORDINATION

Beatriz de Camargo | National Cancer Institute and Ministry of Health, Brazil

Marceli de Oliveira Santos | National Cancer Institute and Ministry of Health, Brazil

#### **SPEAKERS**

Beatriz de Camargo | National Cancer Institute and Ministry of Health, Brazil

Carlos Anselmo Lima | State Department of Health, Sergipe, Brazil

Cynthia Laporte | Municipal Health Secretariat, Curitiba, Brazil

Gemma Gatta | Fondazione IRCCS National Cancer Institute, Italy

Gil Patrus Mundium Pena | State Department of Health, Minas Gerais, Brazil

Marceli de Oliveira Santos | National Cancer Institute and Ministry of Health, Brazil

Nathalie Balmant | National Cancer Institute and Ministry of Health, Brazil

Paulo Cesar Fernandes de Souza | Epidemiological Surveillance in the State

Department of Health, Mato Grosso, Brazil

Rejane de Souza Reis | Hospital Fundação do Câncer, Brazil



#### **SUMMARY**

Pediatric cancer staging is essential for understanding the prognosis of the disease and thus deciding on the best treatment. Pediatric staging, according to the Toronto Childhood Cancer Stage Guidelines, has the objective of establishing a uniform staging system for pediatric tumors. The implementation of this system will promote the comprehension of pediatric cancer within and among different countries, assisting in the creation of strategies for improving the care of pediatric tumors. The course included a discussion on the implementation of this system in Brazil, citing international experiences and presenting a PBCR pilot project in development in 4 Brazilian capital cities.



#### I SEMINAR ON SOCIAL RIGHTS AND PEDIATRIC ONCOLOGY

DATE: 10/02 MORNING

LOCATION: FIRJAN (Av. Graça Aranha, 1 / 4th floor – Centro)

#### COORDINATION

Luciana da Silva Alcântara | National Cancer Institute and Ministry of Health, Brazil Juliana Lyra | Hospital Federal dos Servidores do Estado and Ministry of Health, Brazil

#### **SPEAKERS**

Ana Paula Loures | National Social Security Institute, Brazil

Celina Rodrigues da Silva | State Department of Transportation, Rio de Janeiro, Brazil

Edneusa Maria de Oliveira | State Secretariat for Social Assistance, Rio de Janeiro, Brazil

Rafael Otoni (Palhaço Gorori) | Sociocultural Small Business

Sérgio Henrique Teixeira | State Association of Guardianship Councilors of Rio de Janeiro, Rio de Janeiro, Brazil

#### **MEDIATOR**

Monica Olivar | Núcleo de Saúde do Trabalhador (FIOCRUZ), Rio de Janeiro, Brazil



#### **SUMMARY**

A given cancer treatment's success depends highly on the social support given to the patient. In regards to children, the entire family is involved in the care - and often the mother is the only provider and must abandon her job to dedicate herself to her sick child. This seminar presented the challenges and opportunities involved in bringing hospitals and social program administrators together in an attempt to ameliorate the socioeconomic issues which affect treatment avoidance, as well as the importance of civil society in childhood cancer care and the necessity of bringing support centers together to strengthen the common network of information production.



### WORKSHOP ON GAINING SUPPORTERS FOR CHILDHOOD CANCER

DATE: 10/02 MORNING

LOCATION: FIRJAN (Av. Graça Aranha, 1 / 4th floor – Centro)

#### COORDINATION

Patrícia Elia | Municipal Health Secretariat, Rio de Janeiro

Angela Alves | Municipal Health Secretariat, Rio de Janeiro



#### **SUMMARY**

Rio de Janeiro students looking for training in early cancer diagnosis participated in the workshop. Three cancer cases were presented, and the students formed discussion groups to fill out an action plan. At the end of the workshop, the groups explained their respective plans and debated the referrals and treatments which have occurred in their workplaces, exchanging ideas and solutions for the challenges they have faced.





# **RECOMMENDATIONS (2019-2021)**

#### GT1: ACCESS TO CHILDHOOD CANCER TREATMENT

**DATA: 09/30** 

LOCATION: FIRJAN (Av. Graça Aranha, 1 – Centro)

#### COORDINATION

Sima Ferman | Section Chief of Pediatric Oncology at the National Cancer Institute Marcelo Land | Section Chief of Pediatric Hematology at Instituto de Puericultura e Pediatria Martagão Gesteira (UFRJ)

#### **BRIEF**

Contribute to the implementation of strategies geared toward quick access to childhood cancer treatment; regulation, monitoring, and patient care.



#### WHERE ARE WE NOW?

Early diagnosis is essential to increasing the childhood cancer survival rate. Health professionals must be attentive to signs and symptoms of the disease, the flow of referrals for diagnostic investigation and treatment should be universally recognized, and patient admission should always be immediately guaranteed at the reference centers. In 2019, Instituto Desiderata increased the training for family health teams in Rio de Janeiro state - a total of 608 professionals. For 2020, this number is expected to hit more than 800. Another still unimplemented resource which could support Primary Healthcare professionals with suspected cases is the creation of an e-SUS alert when the patient holds their third consecutive consultation. Regarding the flow of referrals for outpatient consultations, in May of 2019, a meeting was held between Instituto Desiderata, the Superintendência de Regulação, and other partners who work with pediatric oncology - INCA, HFSE, HUPE, HEMORIO, HEC, and CGA/DGH - in which all parties agreed to and created the Pediatric Oncology Screening resource in the Regulation System (SER). This established that the Regulation Protocol would follow the guidelines suggested by United for a Cure. In this way, suspected cases of childhood cancer entered into SER would be sent to service providers within 72 hours. The providers would initially make only a percentage of patient admissions available on SER, so that access was not "closed" by the United for a Cure patients and the hospital's regular demands. Currently, 7 hospitals have the capacity to treat childhood cancer in Rio de Janeiro state, and 4 offer patient admissions as regulated by SER and the Pediatric Oncology Screening resource. While this improvement was important, it is still necessary to move forward so that all hospitals offer patient admissions and so that the 72-hour time window continues to be respected. Another challenge is to define what role United for a Cure holds within Rio de Janeiro city together with the National Regulation System (SISREG).



#### LEADERS | RESPONSIBILITIES **Q** INDICATORS WHERE WE WANT TO BE Guarantee patient admissions from 100% State Department of Health | N. of hospitals with of hospitals with capacity implementation patient admissions to treat childhood regulated by SER. cancer through the State Specialized hospitals | implementation Regulation System (SER), N. of patient admissions Instituto Desiderata | through the Pediatric by hospital per month. articulation and monitoring **Oncology Screening** resource. Protocol approved in CIB. State Department of Health | Formalized and publicized implementation N. of children referred by protocol on pediatric SER. Municipal Health Secretariat | oncology outpatient support regulation in Rio de Janeiro Time between solicitation state, in accordance with of patient admission in Instituto Desiderata | the United for a Cure SER and scheduling of coordination and monitoring program. appointment in specialized Specialized hospitals | support hospital. N. of meetings held between the State State Department of Health | Regulatory Board, Flow of childhood cancer implementation Municipal Regulatory regulation in Rio de Janeiro Board, and Instituto Instituto Desiderata | coordination city and continuity of the Desiderata. and monitoring defined United for a Cure N. of regulated childhood system. State Department of Health | cancer cases/n. of support suspected childhood cancer cases Ministry of Health | implementation Alert from implemented E-SUS alert system created. APS electronic handbook. Instituto Desiderata | monitoring State Department of Health | implementation and coordination N. of Rio de Janeiro state APS professionals trained APS professionals trained in all regions of Rio de Municipal Health Secretariat | every year. Janeiro state regarding implementation suspected childhood N. of trained Rio de Janeiro Instituto Desiderata | cancer cases. state professionals by year. coordination, support, and monitoring

#### GT2: CHILDHOOD CANCER AND PROFESSIONAL TRAINING

**DATA: 09/30** 

LOCATION: FIRJAN (Av. Graça Aranha, 1 – Centro)

#### COORDINATION

Elizabeth Parente | Rio de Janeiro State Pediatric Society Laurenice Pires | Health Manager Instituto Desiderata

#### **BRIEF**

Define inter-institutional strategies to include childhood cancer in the academic training of doctors and nurses and in continued education for health professionals.



#### WHERE ARE WE NOW?

Given that cancer is a relatively rare disease whose signs and symptoms appear to be those of other pediatric illnesses, and that many health professionals, especially doctors and nurses, do not learn about childhood cancer in universities, diagnosis remains a challenge. Health professionals' contact with the theme, from the time they graduate, could be exceptionally valuable. In Rio de Janeiro in 2019, two Public Universities offered an oncology course in their medical and nursing curriculums; only one for medicine and one for nursing. Therefore, the medical and nursing Student Leagues has represented strategic areas for spreading awareness among students, as well as a focal point for action from the Rio de Janeiro State Pediatric Society (SOPERJ) in partnership with Instituto Desiderata. In 2018, activities were held with the Student Leagues of the Estácio de Sá, UNIGRANRIO, UNIRIO, and Severino Sombra (Valença) universities. United for a Cure was presented to the oncology nursing graduate program and at the XIII CONSOPERJ. The training of Family Health Strategy professionals has moved into the rural areas of the state, with the goal of training 1,600 people by the end of 2020. Some professionals were already trained in 2019 in the Metropolitana II region and in Rio de Janeiro city. Training professionals to identify cancer signs and symptoms is part of the State's Permanent Education Plan 2019-2022.



<sup>&</sup>lt;sup>1</sup> Documentary research carried out by Prof. and Dr. Leila L. do Couto using publications available on the state's Public University digital network. Undergraduate course syllabi in nursing and medicine, didactic-pedagogical programs, and course descriptions were selected from the Schools of Nursing and Medicine in 2019.

#### LEADERS | RESPONSIBILITIES **Q** INDICATORS ✓ WHERE WE WANT TO BE Holding two activities per Universities | implementation N. of activities regarding year on childhood cancer childhood cancer held Instituto Desiderata | support in medical and nursing annually by the students SOPERJ | support courses N. of activities regarding Inclusion of pediatric Universities | implementation childhood cancer held oncology in scientific during scientific pediatric pediatric events and Instituto Desiderata | support events and in professional professional training SOPERJ | support training institutions institutions. every year.



#### **GT3: HEALTH DATA**

DATA: 09/30 LOCATION: FIRJAN (Av. Graça Aranha, 1 – Centro)

#### COORDINATION

Evelyn K. dos Santos | Health Analyst at Instituto Desiderata Marceli Santos | Technologist at National Cancer Institute

Rejane Reis | Project Analyst at Brazilian Cancer Foundation

#### **BRIEF**

Design proposals to consolidate the implementation of the Hospital Cancer Registry (HCR) and the Population-based Cancer Registry (PBCR) in Rio de Janeiro, with a focus on standardizing the pediatric registries.



#### WHERE ARE WE NOW?

The Population-based Cancer Registry (PBCR) and the Hospital Cancer Registry (HCR) are two extremely relevant sources of information for understanding the health-related and epidemiological realities of the disease. In Rio de Janeiro, of the 7 hospitals which have the capacity to treat childhood cancer, only one is yet to implement an HCR. Currently, 200 to 300 cases of childhood cancer are registered every year. However, not all hospitals make their records available. Instituto Desiderata, through the National Support Program for Oncology (PRONON) and in partnership with the State Department of Health (SES-RJ), will train HCR registrars in Rio de Janeiro state in 2020.

The Angra dos Reis PBCR is functioning, but the Rio de Janeiro city PBCR, one of the goals of the Oncological Attention Plan, has still not been implemented by the state. Some advances have been made, such as the training of registrars by the State Department of Health in partnership with INCA, and the elaboration of a Work Plan, which would formalize the beginning of registry activities and which awaits the signature of the state health secretary.

Between 2014 and 2015, specialists from various areas related to pediatric oncology gathered in Toronto to standardize the staging of pediatric tumors in a way which is easily reproduced and which can be included in population-based registries around the world. In 2019, Instituto Desiderata completed the first Portuguese translation of the Toronto Consensus.

One challenge for standardization is that the staging registry should be produced by the doctor and not by the registrar. For the Toronto Consensus to be successfully implemented, it is essential that pediatric oncologists are engaged and include the staging in their patients' charts. It is important to emphasize that clinical pediatric staging is different from the cancer registry, but that both are necessary for evaluating the quality of care.

Another essential issue is understanding the situation of private hospitals. Although their use of the HCR is not mandatory, having data from this section will guarantee greater understanding of the reality of pediatric oncological treatment.

✓ WHERE WE WANT TO BE	Q INDICATORS	LEADERS   RESPONSIBILITIES
Standardization of pediatric tumor staging, as recommended by the Toronto Consensus, with adherence by pediatric oncologists and the Brazilian Society of Pediatric Oncology (SOBOPE).	Publication of TNM-8, with a specific chapter on the standardization of pediatric tumor staging.  Pilot project on the Toronto Consensus held in four capitals (Curitiba, Belo Horizonte, Cuiaba and Aracaju).  Meeting with cancer registrars and pediatric oncologists to present the preliminary results of the pilot projects.  Staging (evaluation of the extent of the disease during diagnosis) for studies which evaluate morbidity, survival, etc.	INCA   publication Instituto Desiderata   monitoring and coordination SOBOPE   support
Implementation and updating of HCR in 100% of hospitals with capacity to treat childhood cancer in Rio de Janeiro state and knowledge of the physical structure and process of hospital cancer registries.	Publication of the Pediatric Oncology Overview, with information on hospitals with implemented and updated HCR. Promotion of the report on the physical structure and process of HCR.	SOBOPE   support  National Cancer Institute   publication and research  Instituto Desiderata   monitoring and coordination  Specialized hospitals   support and implementation
Implementation of PBCR in Rio de Janeiro city.	Analysis and monitoring of consolidated databases sent to PBCR.	State Department of Health   implementation  Instituto Desiderata   monitoring  Specialized hospitals   support
Monitoring and promotion of those responsible for carrying out the State Oncological Attention Plan.	Public promotion of the report on the monitoring of and on those responsible for the State Oncological Attention Plan.	State Department of Health   implementation Instituto Desiderata   monitoring

# GT4: BASIC PRINCIPLES OF THE SISTEMA UNICO DE SAUDE AS RELATED TO CHILDHOOD CANCER: PALLIATIVE CARE

DATA: 09/30 LOCATION: FIRJAN (Av. Graça Aranha, 1 – Centro)

#### COORDINATION

Erica Quintans | Psychologist and Consultant for Instituto Desiderata

Juliana Mattos | Psychologist at the Hospital Federal dos Servidores do Estado

Juliana Lyra | Social Worker at the Hospital Federal dos Servidores do Estado

Renata Barros | Doctor at the Hospital Federal dos Servidores do Estado

Thais Nery | Nurse at the Hospital Federal dos Servidores do Estado

#### **BRIEF**

Design strategies for the implementation and development of palliative care in Rio de Janeiro pediatric oncology services.



#### WHERE ARE WE NOW?

Palliative care consists of assistance provided by a multi-disciplinary team. Its objective is to provide relief from suffering in all its forms: physical, psychological, social, and spiritual, thereby positively contributing to quality of life and helping the patient overcome all the phases of treatment. Brazil still lacks a national palliative care policy, although in October 2018, the Ministry of Health published guidelines for organizing integrated, continued palliative care in the SUS healthcare system. According to the document, palliative care should be offered at all levels of care: Basic Care, Home Care, Outpatient Care, as well as Emergency Room, Urgent Care and Hospital Admission. Any patient with a life-threatening disease, whether acute or chronic, is eligible for palliative care upon diagnosis. In Rio de Janeiro, a recent, significant advancement was made with the State Palliative Care Plan in Public Health, approved in June, 2019, by the Legislative Assembly.

However, despite recent normative advancements in the country, the National Association of Palliative Care showed that 74% of these services are offered in hospitals. The Healthcare Network still lacks a policy for the implementation and organization of palliative care at the three levels of care. Brazil still lacks the sufficient, qualified, human resources to be able to adequately offer palliative care. Academic specializations in the area have appeared recently and are generally offered by private institutions, and are thus more expensive for professionals. In Rio de Janeiro, two public advancements are worth highlighting: the Specialized Course in Palliative Care with an Emphasis on Primary Care at the National School of Public Health (FIOCRUZ) and the INCA courses, especially Capacita INCA, are also held in the state's hospital network. Among the hospitals with pediatric oncology services, 4 include formalized palliative care commissions.

Another challenge is the distribution of opioids, carried out by the hospital pharmacies rather than the Popular Pharmacies, which makes patient access more difficult. It is therefore important that the State Palliative Care Plan provide guidelines for decentralizing opioid distribution.

✓ WHERE WE WANT TO BE	Q INDICATORS	LEADERS   RESPONSIBILITIES
Accompaniment of children receiving oncological palliative care by Primary Healthcare network and by hospitals with capacity to care for childhood cancer in an integrated manner.	N. of patients receiving palliative care accompanied by Basic Care network.  N. of strategies created in the palliative care Work Group to coordinate hospitals which treat childhood cancer and Primary Care network.	State Department of Health   implementation  Specialized Hospitals   implementation  Instituto Desiderata   coordination and monitoring
Primary Care network emits 100% of death certificates of children and adolescents with cancer in case of home death.	N. of death certificates for children and adolescents with cancer at home issued by APS.	Municipal Health Secretariat   implementation Instituto Desiderata   monitoring
Ministry of Health to approve and send Primary Care training project for PRONON/MS palliative care.	Project approved by Ministry of Health.	Ministry of Health   Institutional approval Desiderata   monitoring
Availability of palliative care training spaces for hospitals with pediatric oncology capacity.	N. of training courses held by hospitals.	Specialized Hospitals   implementation Instituto Desiderata   support
Publication of the State Palliative Care Plan, including training and guidelines on distribution of opioids.	State Palliative Care Plan published in the federal register, <i>Diário Oficial</i> .	State Department of Health   implementation Instituto Desiderata   monitoring



# **COMMUNICATION**

## **FOP-RIO WEBSITE**



### **MATERIAL**

# BAG



### NAME BAGDES



### **NEWSLETTERS**



#### **SOCIAL MEDIA**



followers on Instagram

supporting institutions promoting the event

cards published on **Facebook** and **Instagram** 



**Event coverage in real time** with text, photos, and live transmissions.

#### PRESS SECRETARY

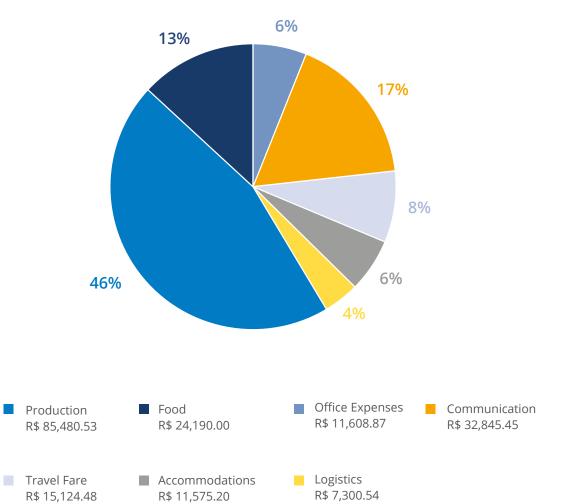
Q TITLE	OUTLET	E CITY
5th Pediatric Oncology Forum debates oncological practices in the public healthcare network	O Debate (on-line)	Belo Horizonte
Pediatric Oncology Forum debates oncological practices in the public healthcare network	O Dia (on-line)	Rio de Janeiro
Pediatric Oncology Forum debates oncological practices in the public healthcare network	Isto É (on-line)	São Paulo
Pediatric Oncology Forum gathers international specialists to discuss public policy	2A+ Farma	São Paulo
Instituto Desiderata holds 5th Pediatric Oncology Forum	Observatório do 3º Setor	São Paulo
Instituto Desiderata holds 5th Pediatric Oncology Forum	Rede Papel Solidário	Not available
Avosos Volunteer President is invited to participate in the Rio de Janeiro Pediatric Oncology Forum	Avosos	Not available



#### FINANCIAL STATEMENT

#### **TOTAL VALUE**

## R\$ 188,125.07



R\$ 7,300.54

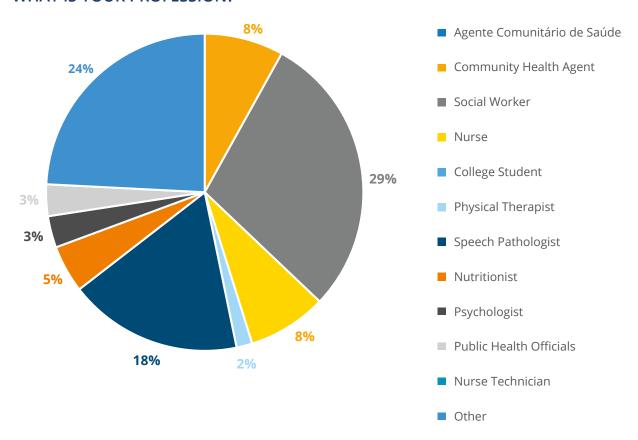
R\$ 11,575.20



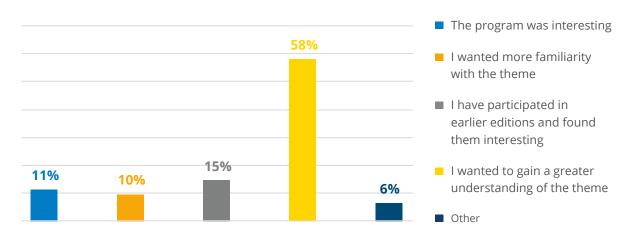
### **POF ATTENDEE PROFILE**

Total: 62 interviewed

#### WHAT IS YOUR PROFESSION?

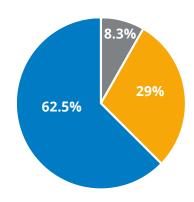


#### WHY WERE YOU INTERESTED IN PARTICIPATING IN THE EVENT?

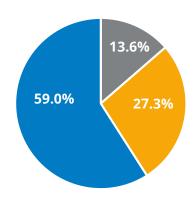


## IF YOU PARTICIPTED IN A WORK GROUP, HOW SATISFIED WERE YOU WITH THE EXPERIENCE?

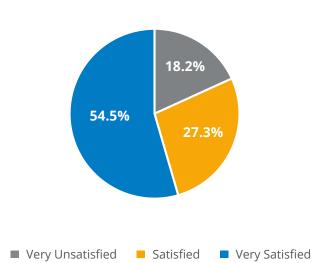
GT1: ACCESS TO CHILDHOOD CANCER TREATMENT



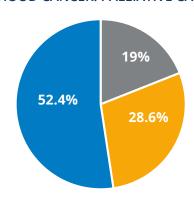
GT2: CHILDHOOD CANCER AND PROFESSIONAL TRAINING



**GT3: HEALTH DATA** 

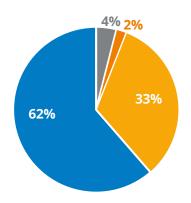


GT4: BASIC PRINCIPLES OF THE SISTEMA UNICO DE SAUDE AS RELATED TO CHILDHOOD CANCER: PALLIATIVE CARE

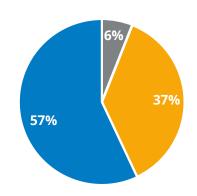


#### HOW SATISFIED WERE YOU WITH THE DISCUSSION AT THE SCIENTIFIC EVENT?

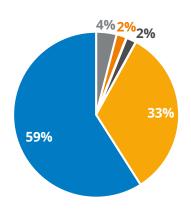
OVERVIEW OF CANCER IN CHILDREN AND ADOLESCENTS: WHERE ARE WE NOW AND HOW DO WE MOVE FORWARD?



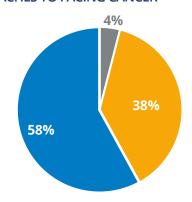
PEDIATRIC ONCOLOGY
HEALTHCARE NETWORKS:
LATIN AMERICAN EXPERIENCES



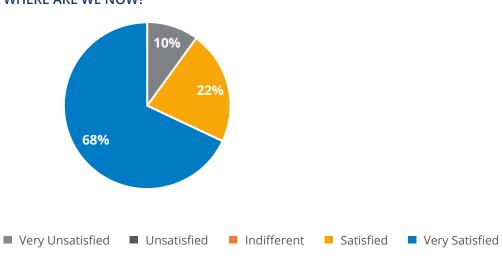
THE IMPORTANCE
OF POPULATION-BASED
CANCER REGISTRIES



INNOVATIONS IN PEDIATRIC ONCOLOGY:
EXPERIENCES WITH INNOVATIVE ADVANCEMENTS
IN CARE, PUBLIC ADMINISTRATION, AND
APPROACHES TO FACING CANCER

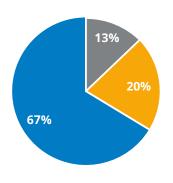


PEDIATRIC PALLIATIVE CARE IN BRAZIL: WHERE ARE WE NOW?

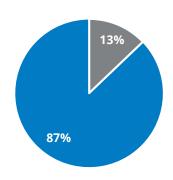


#### HOW SATISFIED WERE YOU WITH THE DISCUSSIONS AT THE SCIENTIFIC EVENT?

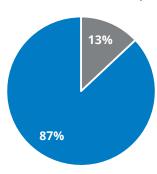
## PEDIATRIC ONCOLOGY COURSE WITH A FOCUS ON THE MULTI-PROFESISONAL PRIMARY CARE TEAM



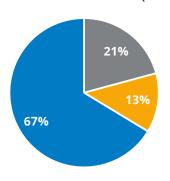
RETINOBLASTOMA MEETING



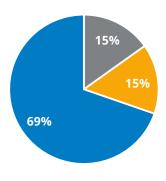
PEDIATRIC PALLIATIVE CARE:
A REALITY UNDER CONSTRUCTION (MORNING)



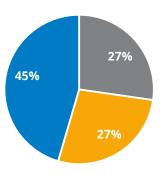
PEDIATRIC PALLIATIVE CARE:
A RELAITY UNDER CONSTRUCTION (AFTERNOON)



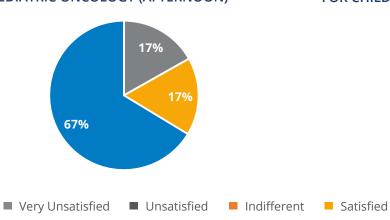
STANDARDIZED STAGING IN CHILDHOOD CANCER



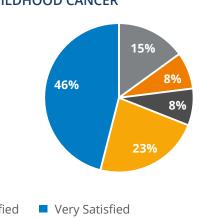
I SEMINAR ON SOCIAL RIGHTS
AND PEDIATRIC ONCOLOGY (MORNING)



I SEMINAR ON SOCIAL RIGHTS
AND PEDIATRIC ONCOLOGY (AFTERNOON)



WORKSHOP ON GAINING SUPPORTERS FOR CHILDHOOD CANCER

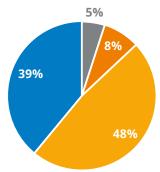


#### HOW DO YOU EVALUETE THE EVENT BASED ON THE FOLLOWING ELEMENTS?

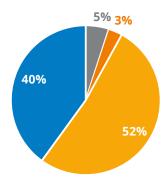
#### RECEPTION BY THE HOST TEAM

# 2% 55%

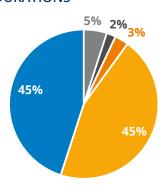
#### MATERIAL RECEIVED BY THE CONFERENCE ATTENDEE



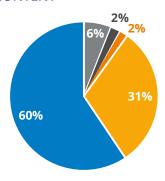
#### **DURATION OF THE EVENT**



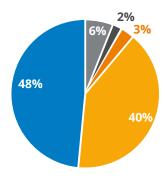
**SPEECH DURATIONS** 



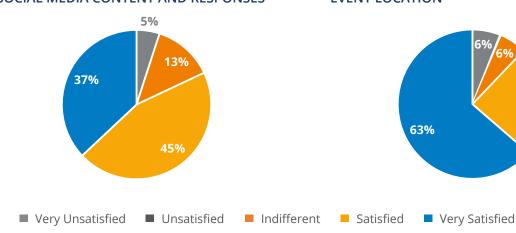
#### **SPEECH CONTENT**



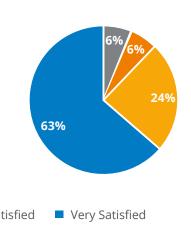
OFFICIAL POF WEBSITE CONTENT AND LAYOUT



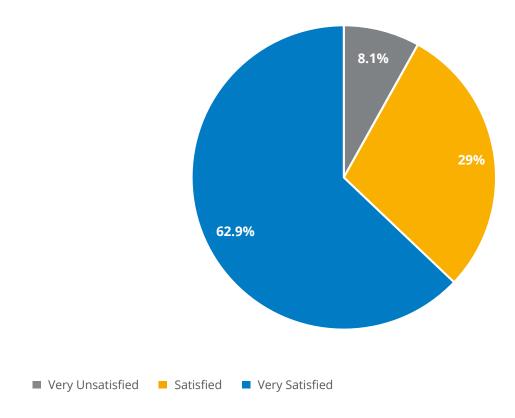
#### **SOCIAL MEDIA CONTENT AND RESPONSES**



**EVENT LOCATION** 



#### HOW WOULD YOU EVALUATE THE EVENT IN GENERAL?



### SUPPORTERS AND PARTNERS

Production

Concept





**Sponsors** 

Institutional Support

















#### Promotion



























