

6º FÓRUM DE ONCOLOGIA PEDIÁTRICA

6th Pediatric Oncology Forum

REPORT



Planning

Execution



UNIDOS
PELA CURA



desiderata

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SCIENTIFIC COORDINATION

Sima Ferman | Instituto Nacional de Câncer (INCA)

TECHNICAL COORDINATION

Roberta Marques | Instituto Desiderata

ORGANIZING COMMITTEE

Alayde Vieira | Universidade Federal do Pará (UFPA)/Secretaria de Estado de Saúde Pública do Pará (SESPA)

Alfredo Scaff | Fundação do Câncer

Ana Lygia Melaragno | Centro Universitário São Camilo/Educare & Onco Ensino e Desenvolvimento

Ana Beatriz Rocha Bernat | Instituto Nacional de Câncer (INCA)

Beatriz de Camargo | Instituto Nacional de Câncer (INCA)

Carolina Motta | Instituto Desiderata

Claudia Bezerra | Instituto Desiderata

Débora Mattos | Instituto Nacional de Câncer (INCA)

Fernanda Lobo Rascão | Instituto de Puericultura e Pediatria Martagão Gesteira (IPPMG/UFRJ)

Flora Watanabe | Hospital Pequeno Príncipe

Isis Magalhães | Hospital da Criança de Brasília José Alencar (HCB)

Joaquim Caetano Aguirre | Santa Casa de Misericórdia de Belo Horizonte

Juliana Mattos | Hospital Federal dos Servidores do Estado (HFSE/RJ)

Karina Ribeiro | Organização Pan-Americana da Saúde (OPAS)

Luiz Fernando Lopes | Hospital de Amor

Mecneide Mendes | Instituto de Medicina Integral Professor Fernando Figueira (IMIP/PE)

Michele da Costa | Instituto Desiderata

Nathalia Grigorovski | Instituto Nacional de Câncer (INCA)

Neviçolino Carvalho | Sociedade Brasileira de Oncologia Pediátrica (SOBOPE)

Patricia Loguetto | St. Jude Children's Research Hospital

Tatiana Santos | Instituto de Puericultura e Pediatria Martagão Gesteira (IPPMG/RJ)

Teresa Fonseca | Confederação Nacional das Instituições de Apoio e Assistência à Criança e ao Adolescente com Câncer (CONIACC)

INTRODUCTION



Held in Rio de Janeiro since 2011, the Pediatric Oncology Forum (FOP) is a biennial space for discussing and proposing actions and policies related to childhood cancer. In its 6th edition, and for the first time in an online format, the FOP has gained a national dimension, with the goal of proposing networking actions that contribute to strengthening national public policies for childhood cancer.

Childhood cancer is a potentially curable disease. However, progress is most evident in high-income countries, where survival rates reach up to 80%. In Brazil, childhood cancer mortality rates have been stable over the past 20 years, and are quite different from region to region. It is necessary for cancer to be considered a priority when addressing the health of children and adolescents.

The 6th FOP is the result of a collective construction. We formed an organizing committee with specialists from all over the country, as well as representatives from PAHO, St. Jude's Hospital, CONIACC and SOBOPE, who collaborated in the construction of this first national FOP. An online platform especially developed for the event allowed for round tables, thematic meetings, and courses to be carried out.

One of the highlights of this edition was the launch of the first National Panorama of Pediatric Oncology, which presented data that

reinforces the importance of a more equitable advancement in childhood cancer policies in Brazil.

At the end of the event, a workshop took place to consolidate effective proposals for the thematic axes: access to the healthcare system, palliative care, monitoring and evaluation, qualification of treatment and advocacy strategies. The intent was to provide information for the implementation of childhood cancer public policies, and with a view towards increasing the chances of cure for children and adolescents in Brazil.

We live in an opportune moment in which PAHO has defined Brazil as one of the priority countries for the implementation of the Global Initiative for Childhood Cancer, launched in 2018 by the World Health Organization (WHO), and which aims to increase the chances of cure to 60% globally by 2030. We need to take advantage of the favorable international context and promote effective strategies so that all children and adolescents diagnosed with cancer in Brazil have the same chances of cure.

It is with great satisfaction that we hope this report will contribute to qualify the debate and promote the necessary joint actions between public managers, health professionals and social organizations to increase the chances of cure for childhood cancer.

Roberta Costa Marques

TECHNICAL COORDINATOR OF THE 6TH FOP
EXECUTIVE DIRECTOR OF INSTITUTO DESIDERATA

Sima Ferman

SCIENTIFIC COORDINATOR OF THE 6TH FOP
HEAD OF PEDIATRIC ONCOLOGY AT THE INSTITU-
TO NACIONAL DO CÂNCER

THE FORUM




THE FOP

IN NUMBERS


874
registered participants


SPEAKERS




53 NATIONAL **6** INTERNATIONAL

639
participants

15 
SUBJECTS ADDRESSED
through courses,
meetings, and debates




 **26 HOURS**
of exclusive content



7 DAYS
of activities

 **A LETTER** of recommendations
for improving the treatment network

MAIN PANELS

IN NUMBERS

   **9 HOURS**
of exclusive
content

SUBJECTS 

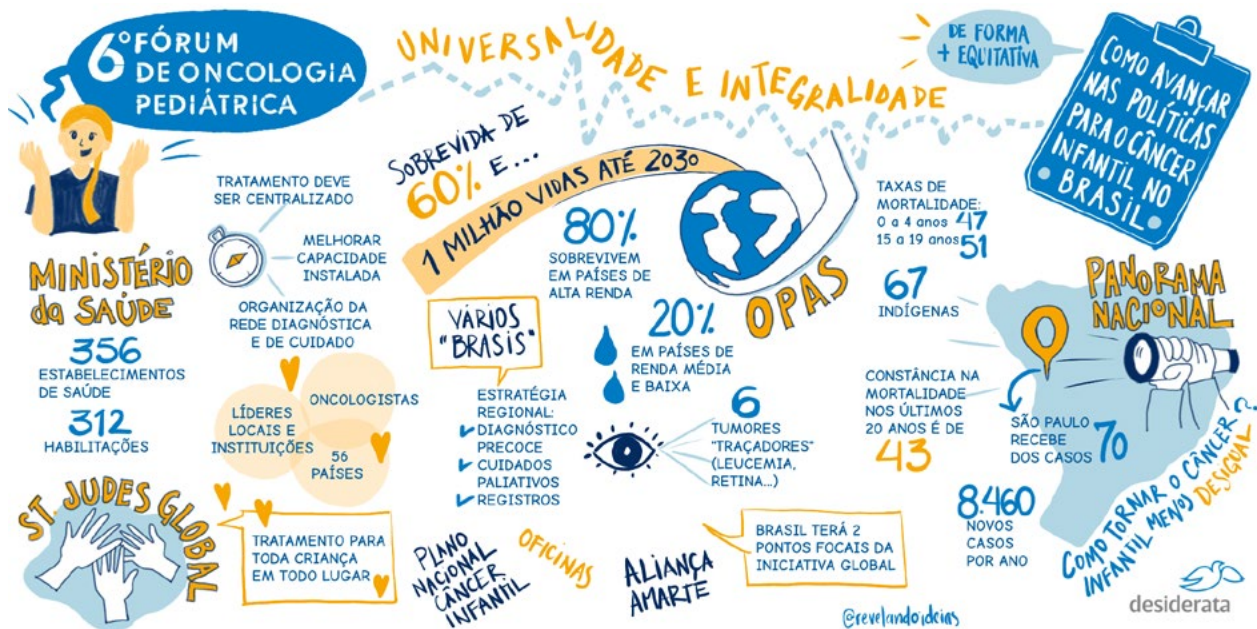
- ² How can we make more equitable advancements in childhood cancer policies?
- ² How can data be used in the management of childhood cancer public policies?
- ² Achievements and challenges in accessing childhood cancer care
- ² Challenges and possibilities for qualifying the diagnosis and treatment of children and adolescents with cancer
- ² Challenges for implementing a palliative care network in Brazil
- ² Advocacy strategies for childhood cancer

31 
SPEAKERS

OPENING PANEL

The opening panel was attended by: Roberta Marques, technical coordinator of the 6th FOP; Sima Ferman, scientific coordinator of the 6th FOP; Neviçolino Carvalho, president of SOBOPE; Rafael Dall Alba, representing PAHO; Gélcio Luiz Quintella, representing INCA; and Maria Inez Gadelha, representing the Ministry of Health. All reaffirmed the importance of the Forum as an extremely relevant space to expand the debate and bring up proposals for the qualification of policies related to childhood cancer.

PANEL | HOW TO ADVANCE MORE EQUITABLY IN POLICIES FOR CHILDHOOD CANCER



SUBJECTS AND SPEAKERS

- 2 National Panorama of Pediatric Oncology – ROBERTA MARQUES (INSTITUTO DESIDERATA)
- 2 Implementation of the Global Initiative for Childhood Cancer in Brazil – KARINA RIBEIRO (OPAS)
- 2 Stronger Together: St. Jude Children’s Research Hospital and its role as a partner in Brazil’s childhood cancer initiatives – MONIKA METZGER (ST. JUDE CHILDREN’S RESEARCH HOSPITAL)
- 2 History of the Ministry of Health’s actions in pediatric oncology and perspectives – MARIA INEZ GADELHA (MINISTRY OF HEALTH)

MEDIATION

AYLENE BOUSQUAT (UNIVERSITY OF SÃO PAULO)

SUMMARY

The opening panel of the 6th Pediatric Oncology Forum highlighted the launch of the National Panorama of Pediatric Oncology, developed by Instituto Desiderata. It also included the presentation of the Global Initiative for Childhood Cancer and its implementation in Brazil by PAHO, in addition to addressing the importance of international partnerships with the aim of increasing the chances of cure in Brazil. Brazil has a significant regional disparity with regard to childhood cancer care, as well as a stagnation in the mortality rate over the years. The panel exposed the need to develop strategies in order to reduce this inequality. There is no isolated solution, and this is why the Unified Healthcare System (SUS) must be strengthened in order to ensure such equity for children and adolescents with cancer throughout Brazil.

PANEL | HOW CAN DATA BE USED IN THE MANAGEMENT OF CHILDHOOD CANCER PUBLIC POLICIES?



SUBJECTS AND SPEAKERS

- 2 **How cancer registry data can help policies targeting childhood and adolescent cancer** – MICHEL COLEMAN (LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE)
- 2 **Pediatric cancer monitoring in Brazil: current situation and perspectives** – MARCELI SANTOS (INCA)
- 2 **What can a HBCR reveal about a pediatric cancer treatment center in Brazil? Can we help with management?** – ARNALDO PIRES (GRAAC)
- 2 **Targeting childhood cancer through the Global Initiative for Cancer Registry Development** – MARION PINHEIRO (GICRCHILD)

MEDIATION

KARINA RIBEIRO (OPAS)

SUMMARY

In this panel, we addressed the fundamental elements for reflecting on the use of data in the management of public policies for childhood cancer. Cancer registries are essential for the organization of healthcare systems. Data on pediatric cancer from a certain territory, if collected continuously and incorporating the social determinants for health, ends up being necessary for the construction and strengthening of public policies and healthcare systems. The epidemiological diagnosis of childhood cancer, aligned with a qualified assistance network, is strategic in order to achieve improvements in the survival of children and adolescents. In the national context, cancer surveillance is carried out through population and hospital-based registries, as well as the system on mortality. The incidence, morbidity and mortality data are the components that subsidize the definition of priorities in the country. Besides the more macro dimension related to the use of information on cancer, when the data on the disease is used in the hospital context and associated with quality indicators, it can be a powerful tool for the qualification of management processes and decision-making in health services.

PANEL | ACHIEVEMENTS AND CHALLENGES IN THE ACCESS TO CHILDHOOD CANCER CARE



SUBJECTS AND SPEAKERS

- 2 **The experience of Unidos pela Cura** – CAROLINA MOTTA (INSTITUTO DESIDERATA)
- 2 **Cascavel's experience in the organization of a pediatric oncology care network** – CARMEM FIORI (HOSPITAL DO CÂNCER DE CASCAVEL)
- 2 **Organization of the network to guarantee children's access to cancer treatment** – SUYANNE MONTEIRO (MINISTÉRIO DA SAÚDE)

MEDIATION

SIMA FERMAN (INCA)

SUMMARY

Two successful initiatives were presented on the organization of the Healthcare Network to ensure access to treatment for childhood cancer. The main points of convergence between these experiences are the training of primary care professionals for the rapid suspicion of childhood cancer, and guaranteeing access to referral centers. The expansion of these experiences to the whole Brazilian territory was a challenge debated at the panel. The speakers discussed the need for the inclusion of pediatric oncology in the state plans for oncologic care, and the importance of support from the Ministry of Health in order to prioritize the subject at a federal level.

PANEL | CHALLENGES FOR THE IMPLEMENTATION OF A PALLIATIVE CARE NETWORK IN BRAZIL



SUBJECTS AND SPEAKERS

- 2 Overview of the current situation of Palliative Care in Brazil – ERICA BOLDRINI (HOSPITAL DE BARRETOS)
- 2 A Brazilian network: the importance of connecting all our palliative cultures – ESTHER FERREIRA (UFSCAR)
- 2 Palliative Care: the impact of continuing education on reducing human suffering DÉBORA MATTOS (INCA)

MEDIATION

FLAVIO ANDRADE (INCA)

SUMMARY

The panel presented an overview on the current situation of Palliative Care in Brazil. According to the atlas of the National Academy of Palliative Care, there are 191 centers in the country that practice palliative care; of these, 76 perform pediatric care. However, palliative care providers are still few and unevenly distributed. Some essential points raised on the qualification of Palliative Care included: investment in the continuing education of professionals, the availability of medication, and the importance of implementing an Integrated Palliative Care Network, with the aim to promote, disclose, and disseminate knowledge on Palliative Care with an interdisciplinary basis.

PANEL | ADVOCACY STRATEGIES FOR CHILDHOOD CANCER



SUBJECTS AND SPEAKERS

- 2 CCI's experience in advocacy for childhood cancer – JOÃO BRAGANÇA (CCI – PORTUGAL) E MARCELA ZUBIETA (CCI – AMÉRICA LATINA)
- 2 Social mobilization to strengthen the national childhood cancer agenda – LILIANA VASQUEZ (OPAS)
- 2 The importance of family members in the qualification of pediatric oncology in Brazil – GERALDO MAIA E JULIANE ALENCAR (ONCOLOGIA INFANTIL NORDESTE)

MEDIATION

TERESA FONSECA (CONIACC)

SUMMARY

Advocacy is an active citizenship practice. This initiative is characterized by the argumentation and defense of causes and rights, being able to influence the creation of effective public policies that benefit the debated topics. The intent of this panel was to present successful advocacy experiences. For example, through the integrated action of civil society, countries such as Chile, Mexico and Peru managed to institute specific laws that improve conditions for the caregivers of children and adolescents undergoing cancer treatment. The panel also debated the importance of the effective participation of family members in the qualification of public policies for childhood cancer. Some important challenges raised were discontinued drugs for the treatment of childhood cancer in Brazil, and the inclusion of new medications approved by ANVISA for the SUS.

PANEL | THE SITUATION OF CHILDHOOD CANCER IN BRAZIL: CHALLENGES AND POSSIBILITIES IN THE QUALIFICATION OF DIAGNOSIS AND TREATMENT FOR CHILDREN AND ADOLESCENTS



SUBJECTS AND SPEAKERS

- 2 Diagnosis of pediatric oncology treatment in Brazil – JEANE TOMAZELLI (INCA)
- 2 Diagnosis of the treatment of adolescents with malignant tumors in Brazil: where are they being treated? BEATRIZ DE CAMARGO (INCA)
- 2 Proposal to equalize diagnosis and treatment of pediatric tumors within the Amarte Alliance LUIZ FERNANDO LOPES (HOSPITAL DE AMOR)
- 2 The importance of centralizing the diagnosis in pediatric oncology – JOAQUIM CAETANO (SANTA CASA DE MISERICÓRDIA DE BELO HORIZONTE)

MEDIATION

ISIS MAGALHÃES (HOSPITAL DA CRIANÇA DE BRASÍLIA)

SUMMARY


This panel discussed the quality of the diagnosis and treatment for childhood cancer, as well as their main challenges and possibilities. The diagnosis of pediatric oncology treatment in Brazil and the specifics of treatment in adolescents and young adults, which represent the highest mortality rate, were presented. Next, two stories of extreme relevance for increasing the chances of cure were reported: the experiences of Aliança Amarte, which seeks to equalize the diagnosis and treatment of pediatric tumors in Brazil, and the cooperative group on renal tumors, illustrating the relevance of an accurate diagnosis to achieve better results. The speakers concluded that the presence of pediatric oncologists in treatment centers for children and adolescents is essential. Another debated point was the number of minimal cases treated at each center. Collaborating in a network presents itself as a possible alternative so that larger centers can support smaller ones in qualifying treatment.


THEMATIC MEETINGS AND COURSES

IN NUMBERS:

33 PARTICIPANTS



 **17 HOURS**
of exclusive content

SUBJECTS 

- ² Early diagnosis of childhood cancer
- ² Pediatric palliative care
- ² The nursing consultation and its contribution to the identification of childhood cancer signs and symptoms
- ² Implementation of the Toronto Guidelines in population-based registries
- ² Possible inventions such as breaks from professional suffering when facing finitude
- ² Impacts of cancer treatment and the challenges of long-term survival
- ² Compassionate community
- ² Pediatric Early Warning Signs Scale in Brazil

THEMATIC MEETINGS

Open spaces for exchanges that took place based on experiences sent by the participants on the respective subject.

SUBJECT | ABOUT LIVING AFTER CHILDHOOD CANCER

SPEAKER

MONICA CIPRIANO (GRAAC)

MEDIATION

NATHALIA GRIGOROVSKI (INCA)

SUMMARY

This meeting was an opportunity to reflect on the impacts resulting from cancer treatment and the challenges of long-term survival. The group highlighted the importance of patients being treated differently, as their demands go beyond medical needs. This highlighted a lack of available care in educational, psychological, and nutritional aspects, among others.

SUBJECT | GATHERING EXPERIENCES ABOUT CARE WHEN FACING FINITUDE: INVENTIONS THAT CAN OFFER BREAKS FROM PROFESSIONAL SUFFERING

SPEAKERS

LUCIANA LOBO (ZEN CÂNCER)
MARLY CHAGAS (UFRJ)

MEDIATION

ANA BEATRIZ ROCHA BERNAT (INCA)
JULIANA MATTOS (HFSE)

SUMMARY

This meeting aimed to promote the exchange of experiences about the possibilities of health professionals, based on their creative skills and finding ways to deal with their suffering during the experience of care in the face of human finitude. Experiences related to music therapy and yoga were presented as significant alternatives for self-care.

SUBJECT | EXPERIENCE OF THE PEDIATRIC EARLY WARNING SIGN SCALE (ESAPP) IN BRAZIL

SPEAKERS

ALEJANDRA MENDES
(NATIONAL UNIT OF PEDIATRIC
ONCOLOGY – GUATEMALA)
JULIANA TEIXEIRA COSTA
(HOSPITAL MARTAGÃO GESTEIRA/BA)

MEDIATION

ANA LYGIA MELARAGNO (EDUCARE &
ONCO ENSINO E DESENVOLVIMENTO)
PATRICIA LOGGETTO (ST. JUDE
CHILDREN'S RESEARCH HOSPITAL)

SUMMARY

In this meeting, the experience of implementing the risk assessment scale in patients admitted to an oncology unit was presented. This was done with the aim of understanding whether the patient is stable or progressing to severity. This scale aims to reduce the time between clinical deterioration and medical interventions; decrease the severity of the disease upon transfer to the ICU; decrease rates of CPAs outside the ICU, and reduce hospital mortality. The speakers highlighted that, in order to support this methodology in hospitals, it is essential to have a professional dedicated directly to the project. Hospitals interested in implementing the methodology along with the St. Jude Hospital Global Alliance should contact Dr. Juliana Costa.

REPORTS AND EXPERIENCES ON EARLY DIAGNOSIS IN PEDIATRIC ONCOLOGY

SPEAKER

SANDRA EMÍLIA ALMEIDA PRAZERES
(ASSOCIAÇÃO PETER PAN)

MEDIATION

SIMA FERMAN (INCA)

SUMMARY

Early diagnosis is essential to improve the chances of cure for childhood cancer. This meeting was an opportunity for dialogue on the use of technology as a facilitating tool to expedite cancer suspicion in children and adolescents. The experience of the Associação Peter Pan was presented, and consisted in developing an application that allows healthcare professionals, patients, family members, and caregivers to have quick and safe access to the main information about childhood cancer. The application also contains a chat that allows for communication between specialists and primary care professionals. The tool is free and available to everyone.

COURSES

EARLY DIAGNOSIS OF CHILDHOOD CANCER WITH A FOCUS ON THE MULTIPROFESSIONAL PRIMARY CARE TEAM

COORDINATION

SIMA FERMAN (INCA)

SPEAKERS

SIMA FERMAN (INCA)

ARISSA IKEDA (INCA)

GABRIELA OINGMAN BELLAS (INCA)

DANIELA LEITE (INCA)

MARIA OURINDA MESQUITA
DA CUNHA (INCA)

FLAVIO ANDRADE (INCA)

SUMMARY

This course addressed the importance of the early diagnosis of childhood cancer, which despite being the first cause of death by disease, is potentially curable if diagnosed early and treated in qualified centers, with specialized multidisciplinary teams and appropriate clinical support. During this course, the specificities on signs and symptoms of solid tumors, central nervous system tumors, and hematological diseases were presented. Important aspects on how to recognize and assist a child who is undergoing cancer treatment or who presents with cancer-related symptoms were also covered. At the end, clinical cases were shown.

THE IMPORTANCE OF PALLIATIVE CARE FROM THE TIME OF DIAGNOSIS

COORDINATION

ANA BEATRIZ ROCHA BERNAT (INCA)
DÉBORA MATTOS (INCA)
FERNANDA LOBO RASCÃO
(IPPMG/UFRJ)
JULIANA MATTOS (HFSE/RJ)
TATIANA VASCONCELOS
DOS SANTOS (IPPMG/UFRJ)

SPEAKERS

ALEXANDRE SILVA
(COMUNIDADE COMPASSIVA)
DÉBORA MATTOS (INCA)
JEANE JUVER (UFF)
LÍVIA COELHO (ANCP/RJ)
JULIANA MATTOS (HFSE/RJ)
FERNANDA LOBO (IPPMG/UFRJ)
PAULA CHAGAS (LADIN E UFJF)
WANÉLIA VIEIRA AFONSO (INJC/UFRJ)
MARIANA SIMONATO (INCA)
VANESSA GONÇALVES (INCA)
JULIANA MENEGUSSI (UFSCAR)
ANA BEATRIZ ROCHA BERNAT (INCA)

SUMMARY

Palliative care is a differentiated approach for patients with a life-threatening illness and their families. It focuses on the control of symptoms and suffering in all dimensions. For this method to be successful and this practice to achieve the best benefits, it is recommended to start soon after the diagnosis.

The course was divided into two parts. The first addressed the current situation of Palliative Care in Brazil, as well as the main barriers for Pediatric Palliative Care, including the myths and truths about the use of opioids and the concept of death in relation to children. It is important to highlight that when a pediatric palliative care team comes into play, an individualized approach can support the patient and family and reduce discomfort and suffering, as well as improve outcomes for families after the death of a child with cancer.

The second part of the course focused on interdisciplinarity, with testimonials and experiences of professionals from different areas who work in palliative care. Currently, the WHO classifies Palliative Care as a set of therapeutic approaches that aim to relieve the symptoms caused by a disease. Palliative Care in Pediatric Oncology should contemplate three levels of intervention: physical, psychosocial, and spiritual. In this sense, it is fundamental to have the integrated work of an interdisciplinary team in order to achieve the best approach for the patient and their family. This may include physicians, nurses, pharmacists, nutritionists, social workers, and psychologists, among other professionals.

IMPLEMENTATION OF THE TORONTO GUIDELINES IN POPULATION-BASED REGISTRIES

COORDINATION

BEATRIZ DE CAMARGO (INCA)
MARCELI DE OLIVEIRA SANTOS (INCA)
REJANE REIS (ABRC)

SPEAKERS

BEATRIZ DE CAMARGO (INCA)
MARCELI DE OLIVEIRA SANTOS (INCA)
REJANE REIS (ABRC)

SUMMARY

Pediatric cancer staging is important to measure the extent of the disease and its prognosis. This course addressed key elements on staging, justifying the importance of its implementation in Brazil. In a simplified way, the standardization of classification in cancer registries aims to systematize the collection of staging data in health institutions. This makes it possible to perform trend, morbidity, and survival analyses on childhood cancer, allowing for comparisons between regions, which is the main objective of the Toronto Consensus. The BENCHISTA Project, which started in England and Italy and was incorporated in the country, proposes to internationally evaluate and compare the stage of diagnosis and survival rates from the data of cancer registries. The results will serve as a basis for the elaboration of practical recommendations to qualify the staging, so as to make it faster and more efficient.

THE NURSING CONSULTATION AND ITS CONTRIBUTION TO THE IDENTIFICATION OF CHILDHOOD CANCER SIGNS AND SYMPTOMS

COORDINATION

ANA LYGIA PIRES MELARAGNO
(EDUCARE & ONCO ENSINO E
DESENVOLVIMENTO)
JULIANA PEPE MARINHO (EDUCARE &
ONCO ENSINO E DESENVOLVIMENTO)
PATRÍCIA MOREIRA (EDUCARE &
ONCO ENSINO E DESENVOLVIMENTO)

SPEAKERS

ANA LYGIA PIRES MELARAGNO
(EDUCARE & ONCO ENSINO E
DESENVOLVIMENTO)
JULIANA PEPE MARINHO (EDUCARE &
ONCO ENSINO E DESENVOLVIMENTO)
PATRÍCIA MOREIRA (EDUCARE &
ONCO ENSINO E DESENVOLVIMENTO)

SUMMARY

The nursing consultation, if performed by professionals with knowledge about the signs and symptoms and the referral processes for immediate care, can contribute to the early diagnosis of childhood cancer. This course was divided into two parts. The first part covered the importance of training nursing professionals to identify the signs and symptoms of cancer, the stages of the nursing consultation, and how a well-documented patient history and thorough examination can detect the disease in an incipient stage, allowing a real chance of cure for the patient. Furthermore, strategies for performing the physical examination in children and adolescents were presented. In the second part of the course, a more in-depth study was proposed regarding the physical exams that must be performed during the nursing consultation, as well as the identification of the signs and symptoms of various types of childhood cancer. Another aspect approached was the importance of supporting the families of children with cancer.

LETTER OF RECOMMENDATIONS



In recent years, several initiatives have been carried out with the aim of increasing the chances of cure for cancer in Brazil. In 2021, the Pan American Health Organization defined Brazil as one of the priority countries for the implementation of the Global Initiative for Childhood Cancer. During this period, SOBOPE collaborated with St. Jude Children's Research Hospital, and held a workshop that sought to expand partnerships between different institutions. This highlighted the importance of developing specific public policies for childhood cancer and adhering to the Global Initiative for Childhood Cancer.

In this context, and considering the relevance of the Pediatric Oncology Forum in bringing forward effective proposals for the implementation of public policies aimed at childhood cancer, in this 6th edition we held a closing workshop with the presence of 56 specialists, who together discussed proposals aimed at increasing the chances of curing childhood cancer in the country.

The workshop aimed to define priorities in the main thematic axes discussed throughout the event: access to the healthcare system, monitoring and evaluation, palliative care, treatment qualification, and advocacy strategies. The participants were divided into groups, and with the presence of a reference specialist and facilitator, defined a priority per topic for the development of an action plan. The tool used was the 5W2H - what, why, who, where, when, how, how much - a set of questions commonly applied to compose action plans quickly and efficiently.

This document presents the results of each group. We hope that the responsible managers will consider the recommendations to consolidate public policies for childhood cancer over the next two years. Instituto Desiderata is committed to disseminating and monitoring the recommendations until the next Pediatric Oncology Forum.

ACCESS TO TREATMENT

Fundamental elements for the organization of the Healthcare Network and ensuring the access of children and adolescents to oncologic treatment.

RELEVANT SUBJECTS RAISED BY THE SPECIALIST

- ² Raising awareness and training primary care for early diagnosis
- ² Integration between the different levels of care
- ² Organization and dissemination of reference and counter-reference flows for childhood cancer
- ² Diagnostic investigation (carrying out exams)

ACCESS TO THE HEALTHCARE SYSTEM	
SUBJECT PRIORITIZED BY GROUP:	Integration between the different levels of care
WHAT?	<ul style="list-style-type: none"> I) Include the topic of Pediatric Oncology in the state oncology care plans; II) Organize the line of care for pediatric oncology in the different states, guaranteeing access to treatment in a timely manner.
WHY?	<ul style="list-style-type: none"> » Guarantee the right to comprehensive, quality, and resolute care; » Reduce late diagnosis; » End the fragmentation of care.
WHERE?	Throughout the entire Brazilian territory, respecting regionalization
WHO?	<ul style="list-style-type: none"> » Ministry of Health; » State and Municipal Departments; » Brazilian Association of Pediatric Oncology; » Instituto Desiderata; » Reference hospitals for pediatric oncology treatment.
HOW?	<ul style="list-style-type: none"> » Raise awareness among public managers about the importance of prioritizing pediatric oncology on the public agenda; » Publish federal norms that include pediatric oncology among the priority axes of the state oncology plans; » Create a committee at the state level to elaborate priority guidelines for organizing the line of care in pediatric oncology; » Publish state deliberations that promote the line of care in pediatric oncology; » Articulate with managers responsible for e-SUS the use of technological tools to facilitate communication between the different levels of care.

MONITORING AND EVALUATION

The use of data from cancer registries as a tool to support the evaluation of public policies for childhood cancer.

RELEVANT SUBJECTS RAISED BY THE SPECIALIST

- ² Lack of political and financial sustainability of cancer registries
- ² Problems related to the quality of the data and training of professional cancer registrars
- ² Problems related to the use of data for management and research

MONITORING AND EVALUATION	
SUBJECT PRIORITIZED BY GROUP:	Lack of political and financial sustainability in cancer registries
WHAT?	<ul style="list-style-type: none"> I) Regulate the system of cancer registries in Brazil (hospital-based and population-based) through a Ministerial Ordinance that establishes the Cancer Surveillance System in Brazil and its components at the federal, state and municipal levels; II) Define the HBCR as part of the Ministry of Health's criteria for accreditation in private programs of excellence; III) Create a culture of dissemination and utilization of the information about cancer obtained through the Cancer Registries.
WHY?	<ul style="list-style-type: none"> » Knowing the epidemiology of childhood cancer is essential in order to inform the planning, monitoring, and evaluation of the disease. » Strengthen policies and scientific research; » Improve the Cancer Registries, as they are the basis for any policy aimed at controlling the disease, from the broad sense of prevention to Palliative Care; » Guarantee the Cancer Surveillance System to monitor cancer control actions.
WHERE?	All over the national territory, in the municipal, state and federal government spheres, as well as private sectors
WHO?	<ul style="list-style-type: none"> » Government in all spheres, hospitals, medical societies, civil society; » Instituto Nacional do Cancer; » National Council of Health Secretaries; » Pan-American Health Organization; » Brazilian Association of Cancer Registries.
HOW?	<ul style="list-style-type: none"> » Create a working group with the SAES to design regulations; » Negotiate with the decision-making spheres (MS and SES) to establish a working group for the incorporation of an HBCR as criteria for Hospitals of Excellence (PROADI); » Specify quality indicators for HBCRs specific to childhood cancer. » Conduct advocacy for health managers in the institutional, municipal, state, and federal spheres;

PALLIATIVE CARE

Priority guidelines for the implementation of an integrated Pediatric Palliative Care network in Brazil.

RELEVANT SUBJECTS RAISED BY THE SPECIALIST

- ² Resistance to include Palliative Care from the time of diagnosis
- ² Difficulty of access to opioids
- ² Difficulty to die at home in Brazil (medication, death certificate)
- ² Lack of space for the subject of Pediatric Palliative Care in professional training
- ² Lack of integration between specialized centers and primary care network at the time of hospital discharge

PEDIATRIC PALLIATIVE CARE	
SUBJECT PRIORITIZED BY GROUP:	Lack of space for the subject of Pediatric Palliative Care in professional training
WHAT?	<ul style="list-style-type: none"> I) Enable the entry of Pediatric Palliative Care into pediatric residencies and pediatric subspecialties; II) Carry out continuing education for students and health professionals in the network as a whole.
WHY?	<ul style="list-style-type: none"> » Limited approach to Palliative Care in the universities; » Few public spaces of continuing education that address the subject.
WHERE?	<ul style="list-style-type: none"> » Universities and teaching hospitals that offer a residency in pediatrics (medical and multiprofessional); » Primary Healthcare at a national level; » Hospitals with pediatric services at a national level; » Universities: student leagues of pediatrics and Palliative Care.
WHO?	<ul style="list-style-type: none"> » Palliative Care Working Group; » Brazilian Pediatric Palliative Care Network » Pediatrics Committee of the National Academy of Palliative Care.
HOW?	<ul style="list-style-type: none"> » Articulate associations and entities, such as the Brazilian Medical Association, Brazilian Association of Pediatric Oncology, Regional Councils of Nursing, Brazilian Association of Pediatrics and the National Academy of Creators and Researchers, with the creation of a joint document that supports the implementation of Pediatric Palliative Care in residency programs. Palliative Care in medical residencies within pediatric subspecialties, besides the reinforcement of making effective the three-year program suggested by SBP, in which pediatric palliative care already exists; » Elaborate document signed by all associations/ entities cited to the National Commission of Medical Residencies (CNRM), for the insertion of Palliative Care in the medical residences within pediatric subspecialties; » Organize a national flow of spots offered to residents in hospitals that offer the Pediatric Palliative Care service. » Develop free courses on Pediatric Palliative Care through the online learning platform for students and healthcare professionals in the network.

QUALIFICATION OF TREATMENT

Essential elements to qualify the treatment of childhood cancer in Brazil in an equitable manner.

RELEVANT SUBJECTS RAISED BY THE SPECIALIST

- 2 Medication
- 2 Access to accurate diagnosis
- 2 Centralization of treatment
- 2 Training of professionals
- 2 Access to new technologies

QUALIFICATION OF TREATMENT	
SUBJECT PRIORITIZED BY THE GROUP:	Access to a precise diagnosis
WHAT?	<ul style="list-style-type: none"> I) To organize a support network among the different centers for the qualification of the diagnosis in pediatric oncology; II) Stimulate and strengthen the cooperative groups, centralizing the review of the diagnosis for all the subjects/ pathologies in pediatric oncology.
WHY?	<ul style="list-style-type: none"> » Ensure uniform access to diagnosis; » Standardize criteria to define the diagnosis; » Enable research with data from networks in development; » Impact directly on the choice of appropriate treatment.
WHERE?	<ul style="list-style-type: none"> » Centers of Excellence/Reference; » The entire network of hospitals that provide treatment in pediatric oncology.
WHO?	<ul style="list-style-type: none"> » Brazilian Association of Pediatric Oncology (also technical support in execution); » Network of SOBOPE associates; » Cooperative groups for the treatment of different pathologies; » Representative of the Ministry of Health and/ or State Departments of Health; » Support: St. Jude Global and Pan-American Health Organization.
HOW?	<ul style="list-style-type: none"> » To perform a situational diagnosis of the services that treat pediatric oncology in the health regions; » Map the strengths and diagnostic needs of each center; » Train the professionals involved in the collection and packaging of the minimum information required in a clinical report; » Establish collaborative networks of specialized diagnosis by pathology, with support from the Ministry of Health and SOBOPE; » Identify programs and/ or stable funding sources to support centers that do not have access to certain types of diagnostics because of the cost of the exam or courier.

ADVOCACY STRATEGIES

The importance of advocacy in strengthening the childhood cancer agenda permanently in public management.

RELEVANT SUBJECTS RAISED BY THE SPECIALIST

- ² Impact of the pandemic on research and treatment of chronic diseases
- ² Lack of consensus on the need for specific policies for childhood cancer
- ² Insufficient assistance policies for families facing childhood cancer
- ² Medication shortages
- ² Absence of strategies to ensure post-treatment care

ADVOCACY	
SUBJECT PRIORITIZED BY THE GROUP:	Insufficient assistance policies for families facing childhood cancer
WHAT?	Aproximar e envolver os familiares, as organizações e a sociedade em geral para fortalecer ações de <i>advocacy</i> .
WHY?	<ul style="list-style-type: none"> » Lack of a national mobilization to fight childhood cancer; » Lack of a consensus on the specific needs of childhood cancer; » Avoidable deaths, years of life gained, more active people, and less of a burden on the healthcare system;
WHERE?	Strategies in the regional and national spheres
WHO?	<ul style="list-style-type: none"> » National Confederation of Support and Assistance Institutions for Children and Adolescents with Cancer, and other civil society organizations; » Family members; » Brazilian Association of Pediatric Oncology; » Social workers.
HOW?	<ul style="list-style-type: none"> » Realizar Conduct a survey of all policies to support families of children with cancer and identify assistance needs; » Learn from successful international experiences; » Create a unique narrative to fight childhood cancer; » Create mobilizing communication strategies; » To carry out education and awareness actions on the subject for the empowerment of families; » Carry out periodic meetings with family members aware of the subject.

COMMUNICATION



WEBSITE

FOP FÓRUM DE ONCOLOGIA PEDIÁTRICA

Idealização UNIDOS PELA CURA Realização desiderata

1º FOP | 2011 2º FOP | 2013 3º FOP | 2015 4º FOP | 2017 5º FOP | 2019 6º FOP | 2019

EM BREVE Relatório final

O Fórum de Oncologia Pediátrica (FOP) é um espaço coletivo bienal onde acontecem trocas de experiências, discussões e são geradas propostas para a (re)definição de políticas públicas que garantam diagnóstico precoce, acesso rápido e tratamento de qualidade para o câncer infantojuvenil. Ao final do evento, essas propostas são consolidadas na Carta de Recomendações que é enviada aos gestores de saúde, representantes de universidades e organizações não governamentais a fim de nortear as ações relacionadas ao câncer infantil no Brasil. Os avanços que ocorrem a partir desse documento são monitorados pelo Instituto Desiderata, e, a cada

FOP FÓRUM DE ONCOLOGIA PEDIÁTRICA

1º FOP | 2011 2º FOP | 2013 3º FOP | 2015 4º FOP | 2017 5º FOP | 2019 6º FOP | 2019

6º FÓRUM DE ONCOLOGIA PEDIÁTRICA

Nos vemos em 2023!

O Fórum de Oncologia Pediátrica (FOP) é um espaço coletivo bienal onde acontecem trocas de experiências, discussões e são geradas propostas para a (re)definição de políticas públicas que garantam diagnóstico precoce, acesso rápido e tratamento de qualidade para o câncer infantojuvenil. Ao final do evento, essas propostas são consolidadas na Carta de Recomendações que é enviada aos gestores de saúde, representantes de universidades e organizações não governamentais a fim de nortear as ações relacionadas ao câncer infantil no Brasil. Os avanços que ocorrem a partir desse documento são monitorados pelo Instituto Desiderata, e, a cada

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1º FOP | 2011 2º FOP | 2013 3º FOP | 2015 4º FOP | 2017 5º FOP | 2019 6º FOP | 2019

6º FÓRUM DE ONCOLOGIA PEDIÁTRICA

UNIVERSALIDADE E INTEGRALIDADE

60% E... 1 MILHÃO MAIS ATE 2035

80%... 20% OPAS

67... 43... 8460

desiderata

6º FOP | 2021

Objetivo:
Propor ações em rede que contribuam para o fortalecimento de políticas públicas nacionais para o câncer infantojuvenil.

Coordenadora Científica:
Sima Ferman

Data:
Entre os dias 4 e 14 de agosto de 2021

PALESTRANTES	COMISSÃO ORGANIZADORA	MESAS	CURSOS
ENCONTROS TEMÁTICOS	PATROCÍNIO	RELATÓRIO GERAL (em Breve)	PRODUTO DA OFICINA (em Breve)

PALESTRANTES

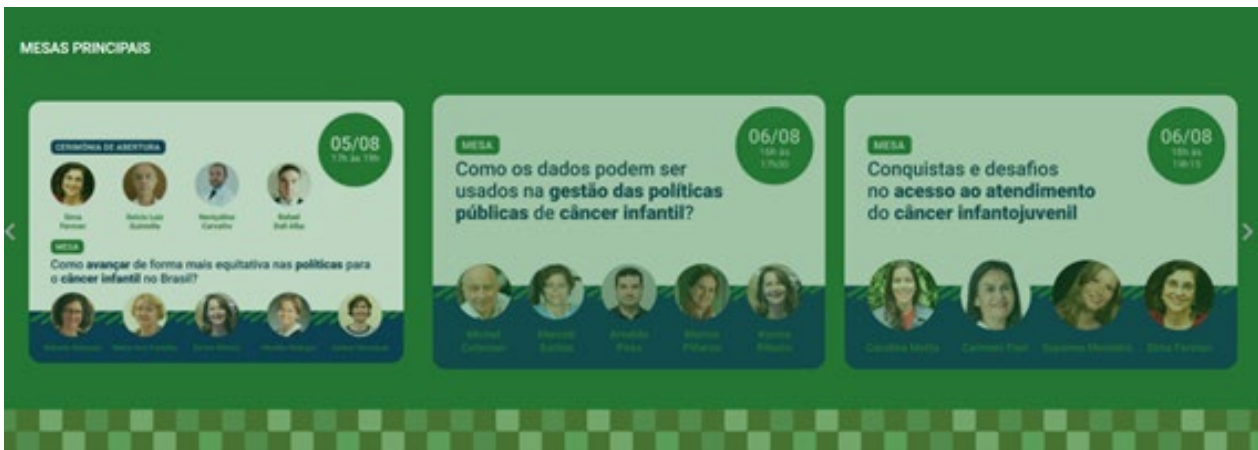
Alexandre Silva
Especialista em Hematologia, Especialista em Saúde Infantil e Cuidado Paliativo, Mestrado e Doutorado na área de Saúde Coletiva, pós-graduação em Saúde Pública (USP), Universidade Católica Portuguesa, Professor Adjunto da Universidade Federal do Rio de Janeiro, Pós-graduação em Hematologia e Medicina, Mestrado e Doutorado em Ciências da Saúde, Universidade Federal do Rio de Janeiro, Pós-graduação em Saúde Pública (USP) e do Observatório português em cuidados paliativos, Membro do Comitê de cuidados paliativos do Conar-MG.

Ana Beatriz Rocha Bernardi
Psicóloga, Pós-graduada em Saúde Psicológica pelo Departamento de Terapia Psicológica da UFPA, Especialista em Clínica Psicanalítica pelo IUPERJ e em Atendimento Psicanalítico em Instituto (IP) do IUPERJ, Psicóloga do Hospital de Câncer 11 de Junho da Rede de Oncologia Pediátrica do Instituto Nacional de Câncer José Aécio Gomes de Silva.

Ana Lúcia Pires Matrangola
Especialista em Oncologia, MSc em Saúde Epidemiológica pelo Departamento de Saúde, Mestre em Ciências pela Universidade Federal do Rio de Janeiro, Doutora em Desenvolvimento de Políticas Profissionais e de Trabalho em Enfermagem da Associação Brasileira de Enfermagem, Doutora Científica da Educação e Docência em Enfermagem, Presidente do Comitê de Enfermagem do SUS/UFPA, Coordenadora Científica no Centro Universitário São Camilo, Fundadora do Projeto Oncopiel em Ação.

Arturo Rueda Escobar
Título de Especialista em Oncologia Pediátrica pela Sociedade Brasileira de Oncologia Pediátrica, Mestrado em Oncologia pelo Instituto Nacional de Câncer, Doutorando em Oncologia pelo Instituto Nacional de Câncer, Médico da clínica de Serviço de Oncologia Pediátrica do Instituto Nacional de Câncer, Coordenadora do Programa de Residência Médica em Oncologia Pediátrica do Instituto Nacional de Câncer, Médica infante do Serviço de Oncologia Pediátrica do Hospital do Síndrome de Estrogênio, Médica assistente de Oncologia Pediátrica do Hospital Quinta D'Or.

CUSTOMIZED PLATFORM FOR THE EVENT



SOCIAL NETWORKS

53 CARDS AND VIDEOS POSTED
on Instituto Desiderata's Instagram, Facebook, and LinkedIn

CREATION OF A FACEBOOK GROUP FOR THE EVENT:

304 FOLLOWERS **25** PUBLICATIONS

17 NEWSLETTERS SENT
to the FOP participants and Instituto Desiderata's mailing list

2 SPONSORS
+
4 INSTITUTIONAL PARTNERS
+
3 COMMUNICATION PARTNERS
= **9** INSTITUTIONS PROMOTING THE EVENT

POSTED CARDS

The image displays ten promotional cards for the 6th Pediatric Oncology Forum (FOP). The cards are arranged in two rows of five. Each card features the FOP logo and specific event details:

- Card 1 (MESA):** "Como avançar de forma mais equitativa nas políticas para o câncer infantil no Brasil?" (How to advance in a more equitable way in policies for childhood cancer in Brazil?). Moderator: Antonio Bonaguidi. Date: 05/08, 17h30 às 19h.
- Card 2:** "Inscrições abertas para o 6º Fórum de Oncologia Pediátrica" (Registrations open for the 6th Pediatric Oncology Forum). Dates: 4 A 14 DE AGOSTO. Registration: foprio.org.br.
- Card 3:** "O 6º Fórum de Oncologia Pediátrica está chegando!" (The 6th Pediatric Oncology Forum is coming!). Dates: 04 A 14 DE AGOSTO. Registration: foprio.org.br.
- Card 4 (MESA):** "Conquistas e desafios no acesso ao atendimento do câncer infantojuvenil" (Achievements and challenges in access to care for childhood cancer). Includes a video call interface.
- Card 5 (ENCONTRO TEMÁTICO):** "Sobre viver após o câncer infantojuvenil" (About living after childhood cancer). Includes a video call interface.
- Card 6 (CURSO):** "A importância dos cuidados paliativos desde o diagnóstico" (The importance of palliative care since diagnosis). Includes a video call interface.
- Card 7:** "Confira o resultado da primeira semana do 6º FOP" (Check the results of the first week of the 6th FOP). Includes a video call interface.
- Card 8:** "Esse ano o nosso encontro vai ser on-line e nacional!" (This year our meeting will be online and national!). Registration: foprio.org.br.
- Card 9:** "Oficina Produto Fórum" (Product Forum Workshop). Date: 14/08, 9h às 12h. Registration: fop.desiderata.com.

NEWSLETTERS

Como avançar de forma mais equitativa nas políticas para o câncer infantil no Brasil?

Este artigo é uma tradução adaptada do artigo "Fogão de Cozinha: Políticas de Saúde para a Criança" publicado no periódico da IOP, edição de maio de 2017.

As políticas públicas de saúde são essenciais para a melhoria da qualidade de vida e a redução das desigualdades. Este artigo discute as políticas públicas de saúde para a criança e o adolescente, com foco na equidade e no acesso a serviços de saúde.

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Estratégias de advocacy para o câncer infantil

Você sabe o que é advocacy e como ele pode contribuir para melhorar as políticas públicas para o câncer em crianças e adolescentes?

Este artigo discute as estratégias de advocacy para o câncer infantil, com foco na participação da sociedade civil e na influência das políticas públicas.

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Vem aí a 6ª edição do FOP!

Forum de Oncologia Pediátrica em São Paulo e no Rio de Janeiro

O Instituto Desiderata realizará, em agosto, a 6ª edição do Fórum de Oncologia Pediátrica (FOP) em São Paulo e no Rio de Janeiro. Este fórum é uma oportunidade para profissionais da área discutirem as mais recentes descobertas e tendências em oncologia pediátrica.

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A importância dos cuidados paliativos desde o diagnóstico - Parte 1

Diagnóstico precoce do câncer infantil com foco no Impacto Multidimensional da Atenção Primária

A consulta de enfermagem e sua contribuição para a identificação de sinais e sintomas do câncer infantil - Parte 1

Sobre viver após o câncer infantjuvenil

Coilando experiências sobre a saúde no momento da falência - Invenções possíveis como brechas para o aprimoramento profissional

PRESS OFFICE

- 2 Oncogeria - 6th Pediatric Oncology Forum discusses public policies for childhood cancer
- 2 Folha de São Paulo - Childhood cancer death rate in Brazil is twice that of the USA

saúde

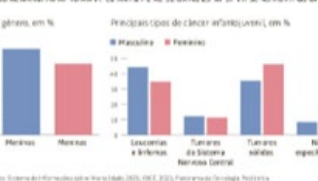
Taxa de morte por câncer infantil no Brasil é duas vezes a dos EUA

Problemas de acesso e falhas de assistência levam país a manter índice estagnado há 20 anos

Cláudia Colucci

Até mesmo a assistência diagnóstica ao paciente de acesso restrito tem sido comprometida em muitos aspectos, como a falta de exames de imagem e a falta de medicamentos para o tratamento.

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Em comparação com o Brasil, os EUA têm uma taxa de mortalidade por câncer infantil muito menor, o que é atribuído a um sistema de saúde mais robusto e a um acesso mais amplo a serviços de saúde.

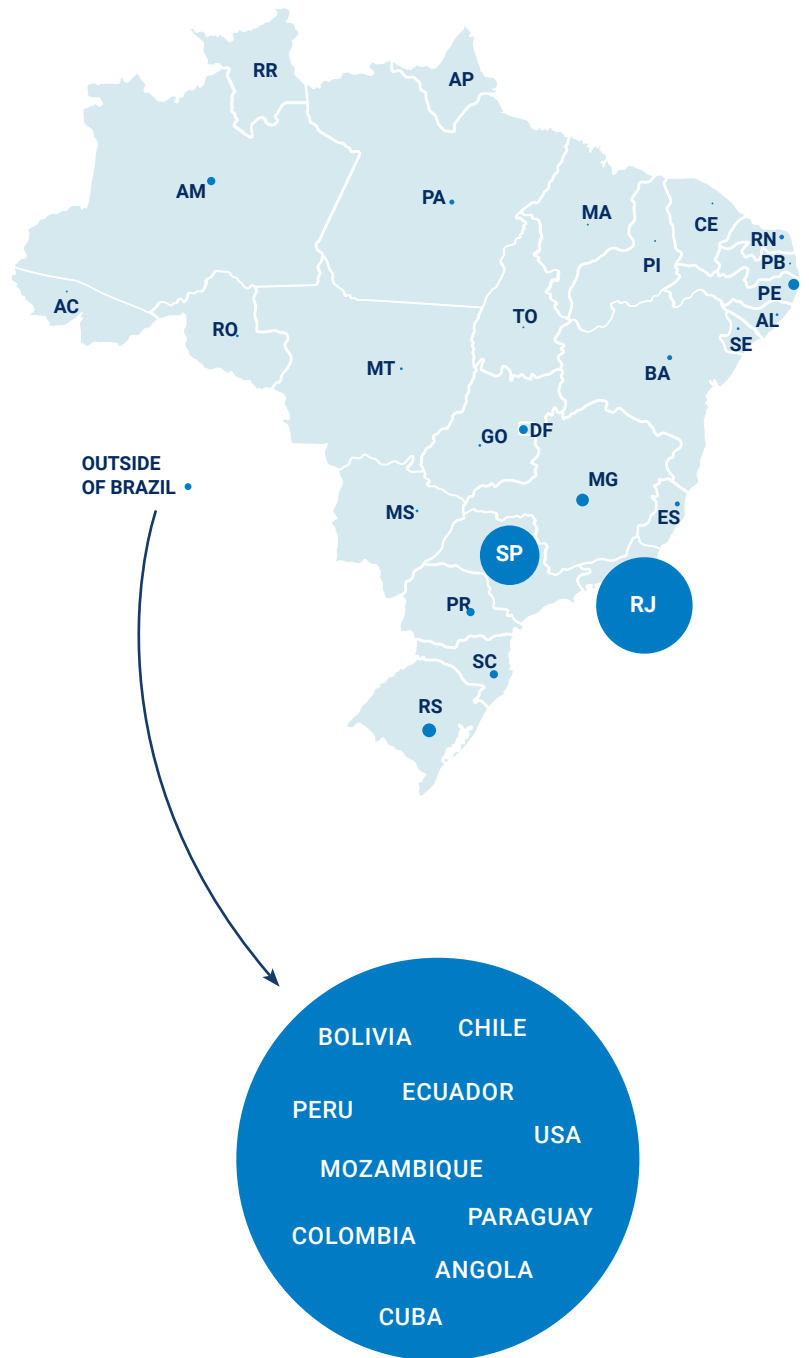
Em comparação com o Brasil, os EUA têm uma taxa de mortalidade por câncer infantil muito menor, o que é atribuído a um sistema de saúde mais robusto e a um acesso mais amplo a serviços de saúde.

PROFILE OF REGISTERED PARTICIPANTS

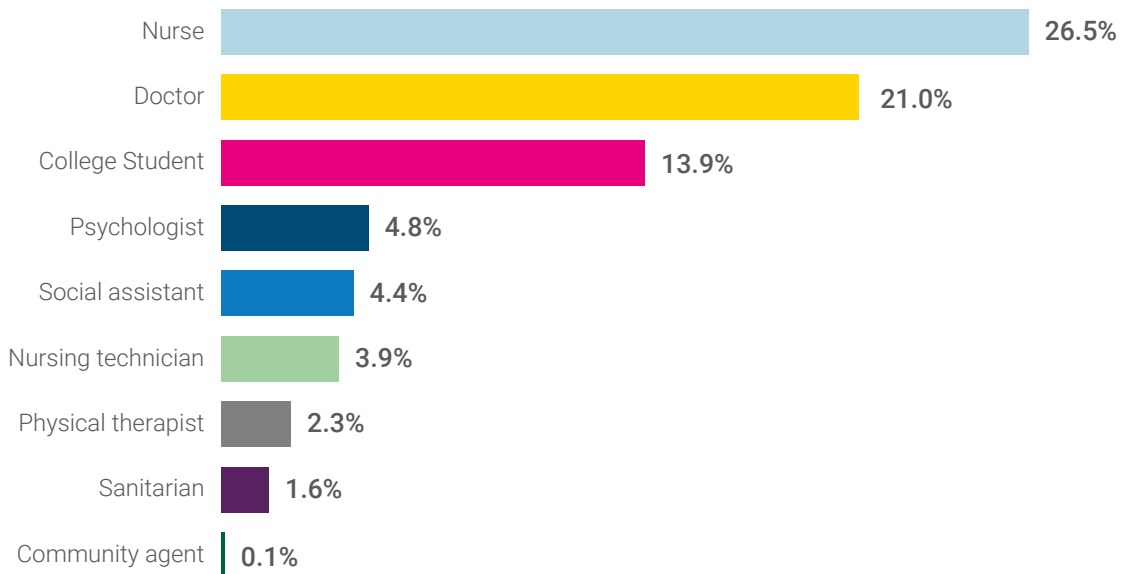


DISTRIBUTION OF PARTICIPANTS ACCORDING TO STATE

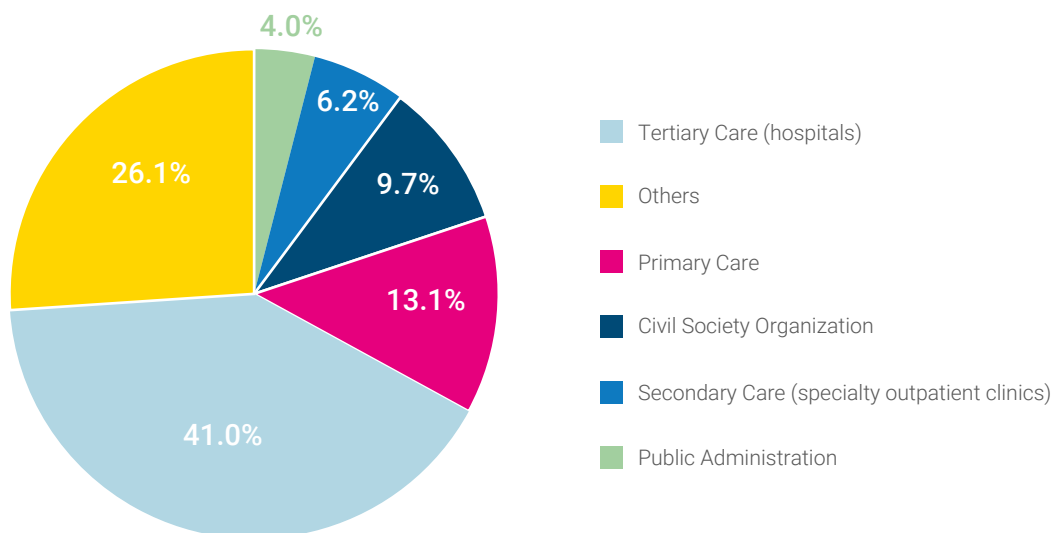
STATE	N	%
AC	2	0.2%
AL	5	0.6%
AM	24	2.9%
BA	14	1.7%
BR	1	0.1%
CE	7	0.8%
DF	26	3.2%
ES	14	1.7%
GO	3	0.4%
MA	3	0.4%
MG	38	4.6%
MS	5	0.6%
MT	8	1.0%
PA	13	1.6%
PB	2	0.2%
PE	52	6.3%
PI	3	0.4%
PR	24	2.9%
RJ	289	35.0%
RN	14	1.7%
RO	7	0.8%
RR	1	0.1%
RS	41	5.0%
SC	24	2.9%
SE	7	0.8%
SP	178	21.6%
TO	1	0.1%
OUTSIDE OF BRAZIL	19	2.3%
TOTAL	825	100%



DISTRIBUTION OF PARTICIPANTS ACCORDING TO PROFESSION

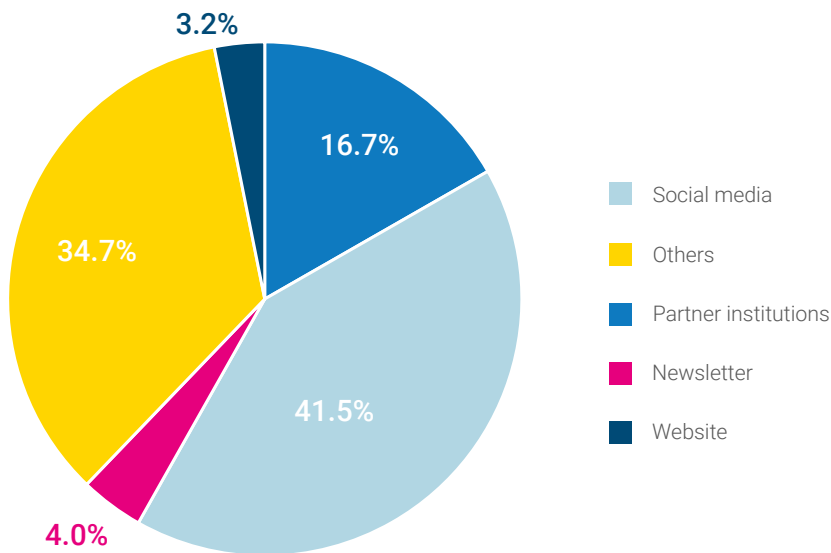


DISTRIBUTION OF PARTICIPANTS ACCORDING TO FIELD OF PRACTICE





HOW REGISTERED PARTICIPANTS HEARD ABOUT THE EVENT



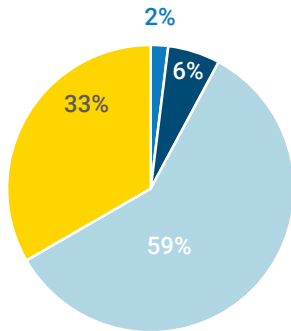
EVALUATION



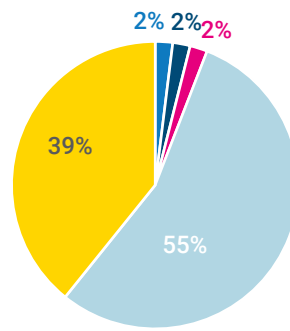
HOW WOULD YOU RATE THE 6TH FOP IN THE ITEMS BELOW?

TOTAL OF PARTICIPANTS THAT EVALUATED THE EVENT: 51

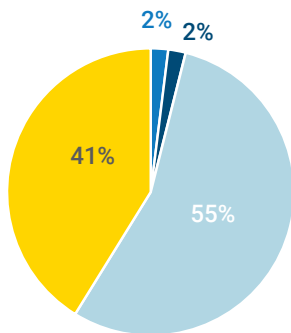
DURATION OF THE EVENT



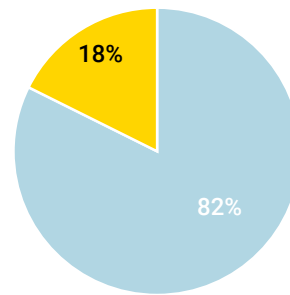
TIME OF THE LECTURES



DURATION OF THE LECTURES

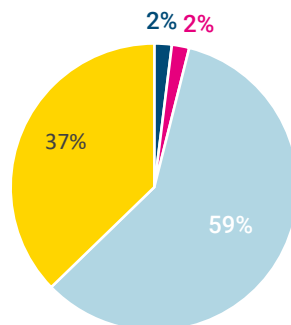


CONTENT OF THE LECTURES

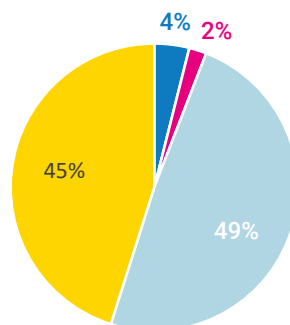


HOW WOULD YOU EVALUATE THE EVENT PLATFORM?

CONTENT PROVIDED



EASE OF FINDING INFORMATION



very satisfied

satisfied

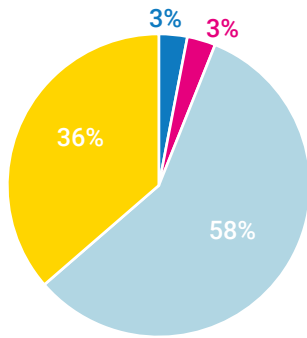
indifferent

unsatisfied

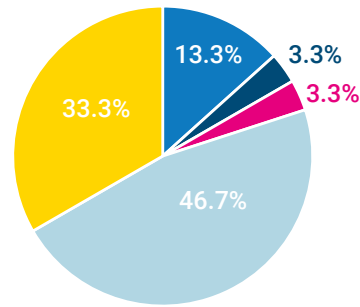
very unsatisfied

IF YOU PARTICIPATED IN A COURSE, WHAT IS YOUR LEVEL OF SATISFACTION?

EARLY DIAGNOSIS OF CHILDHOOD CANCER WITH A FOCUS ON THE MULTIDISCIPLINARY TEAM IN PRIMARY CARE

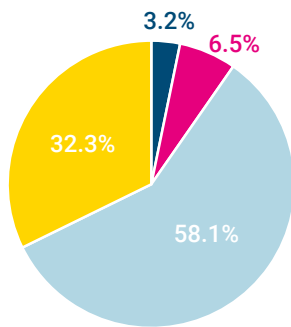


IMPLEMENTATION OF THE TORONTO GUIDELINES IN POPULATION-BASED REGISTRIES

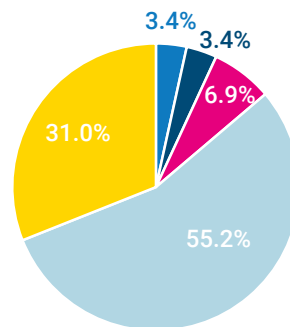


THE IMPORTANCE OF PALLIATIVE CARE FROM THE TIME OF DIAGNOSIS

PART 1

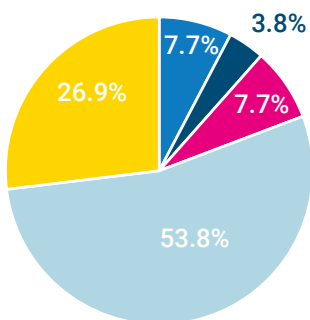


PART 2

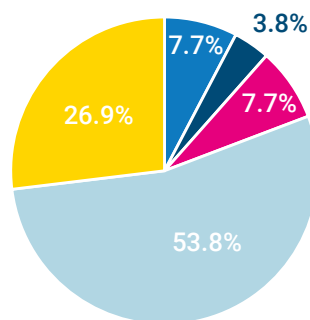


THE NURSING CONSULTATION AND ITS CONTRIBUTION TO THE IDENTIFICATION OF CHILDHOOD CANCER SIGNS AND SYMPTOMS

PART 1



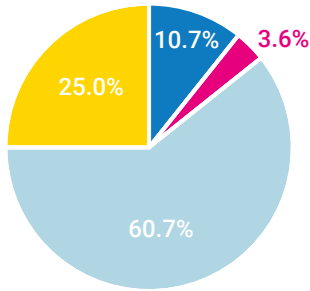
PART 2



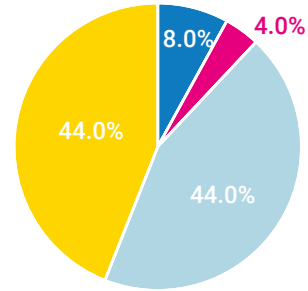
■ very satisfied
 ■ satisfied
 ■ indifferent
 ■ unsatisfied
 ■ very unsatisfied

IF YOU PARTICIPATED IN A THEMATIC MEETING, WHAT IS YOUR LEVEL OF SATISFACTION?

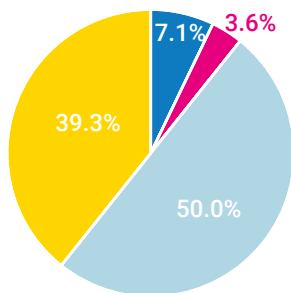
GATHERING EXPERIENCES ABOUT CARE WHEN FACING FINITUDE- INVENTIONS THAT CAN OFFER BREAKS FROM PROFESSIONAL SUFFERING.



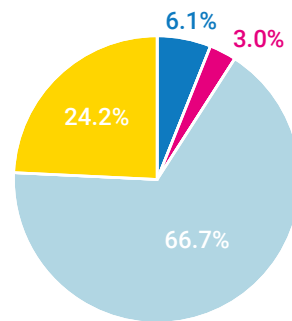
EXPERIENCE OF THE PEDIATRIC EARLY WARNING SIGN SCALE (ESAPP) IN BRAZIL



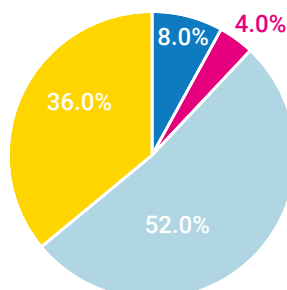
REPORTS AND EXPERIENCES ON EARLY DIAGNOSIS IN PEDIATRIC ONCOLOGY



SURVIVING AFTER CHILDHOOD CANCER



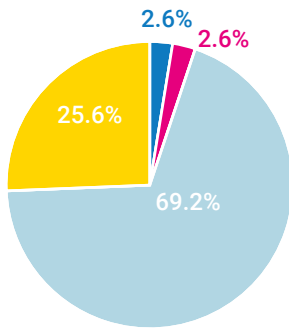
COMPASSIONATE COMMUNITY – PALLIATIVE CARE IN THE FAVELAS



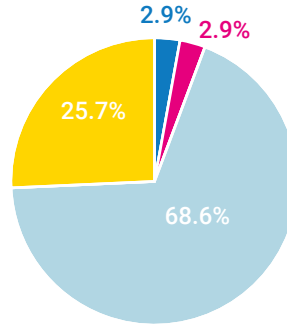
■ very satisfied
 ■ satisfied
 ■ indifferent
 ■ unsatisfied
 ■ very unsatisfied

EVALUATION OF THE PANELS

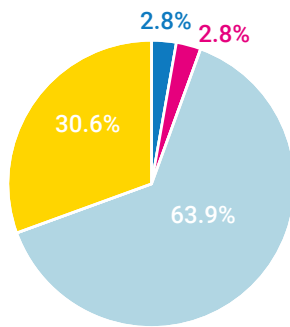
HOW CAN DATA BE USED IN THE MANAGEMENT OF CHILDHOOD CANCER PUBLIC POLICIES?



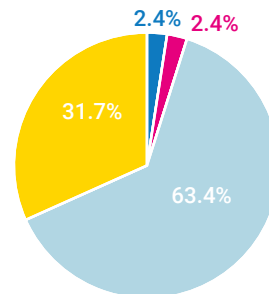
ACHIEVEMENTS AND CHALLENGES IN ACCESSING CHILDHOOD CANCER CARE



CHALLENGES FOR IMPLEMENTING A PALLIATIVE CARE NETWORK IN BRAZIL



THE SITUATION OF CHILDHOOD CANCER IN BRAZIL, CHALLENGES AND POSSIBILITIES FOR THE QUALIFICATION OF DIAGNOSIS AND TREATMENT OF CHILDREN AND ADOLESCENTS



very satisfied

satisfied

indifferent

unsatisfied

very unsatisfied

FOP EVALUATION

Score from 0 to 10 on the items below:

Was the 6th FOP able to potentiate your knowledge on the subject?

9,1

Was the 6th FOP able to provide networking and new connections?

8,2

Would you recommend the 6th FOP to a friend?

9,7

What score would you give the 6th FOP?

9,5

WOULD YOU PARTICIPATE AGAIN?



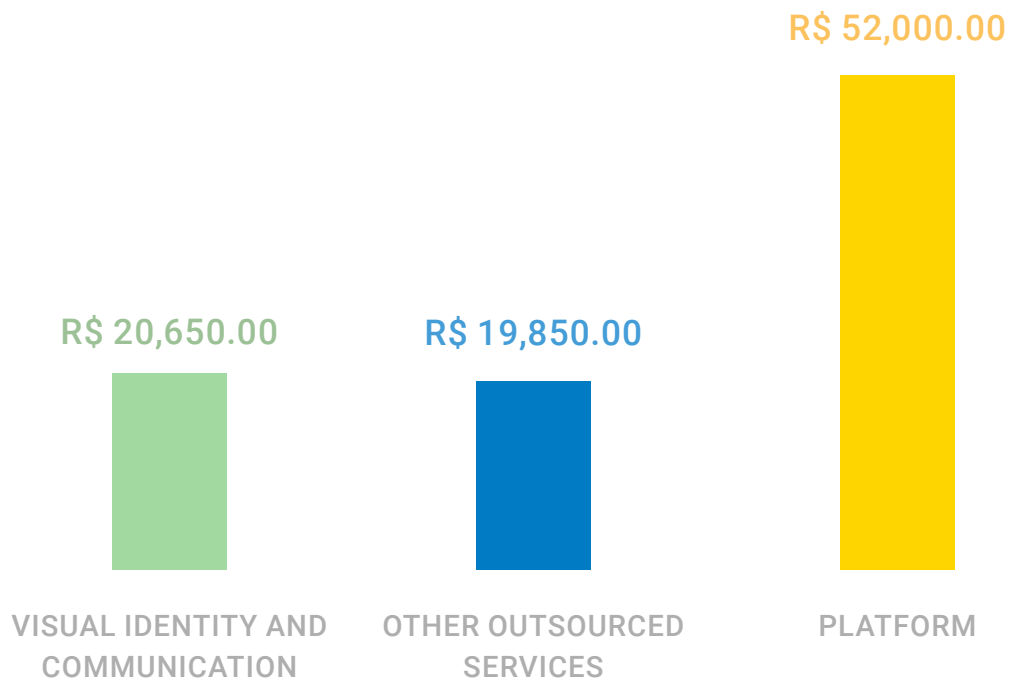
ACCOUNTING



ACCOUNTING

TOTAL AMOUNT:

R\$ 92,500.00



SUPPORTERS AND PARTNERS

PLANNING



EXECUTION



SPONSORS



INSTITUTIONAL PARTNERS



COMMUNICATION PARTNERS



Planning



Execution

