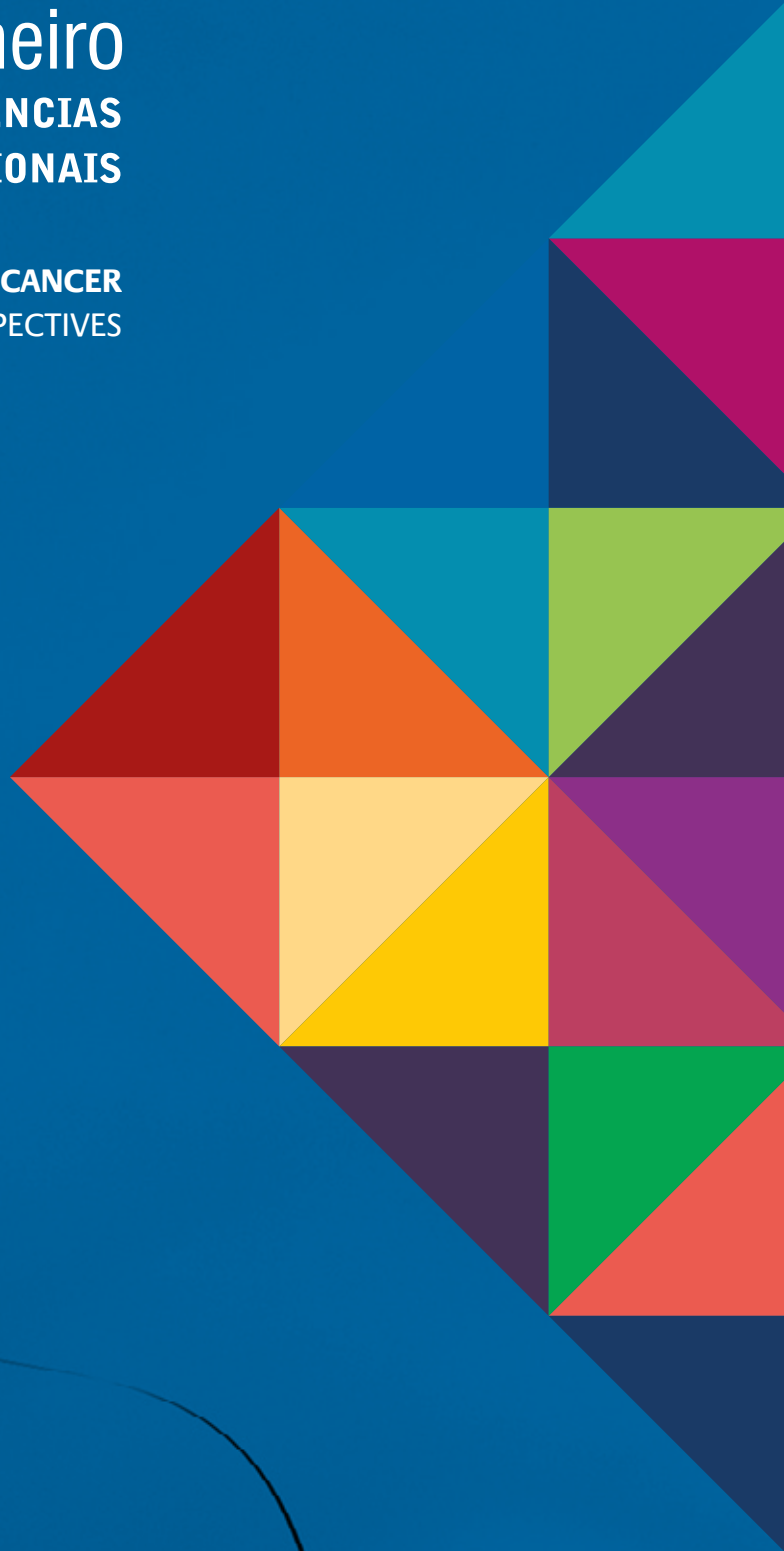


4º Fórum de **Oncologia Pediátrica** do Rio de Janeiro

UM OLHAR SOBRE AS EXPERIÊNCIAS
NACIONAIS E INTERNACIONAIS

THE 4TH RIO DE JANEIRO FORUM ON CHILD CANCER
NATIONAL AND INTERNATIONAL PERSPECTIVES



instituto **desiderata**

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FORUM ON CHILD CANCER



FORUM ON CHILD CANCER

FORUM ON CHILD CANCER IS held every two years during which debates and discussions take place among health professionals, students, and other members and institutions in society. The objective of the Forum is to generate proposals that can help redefine and implement public policies that guarantee early diagnosis of child cancer, and fast access to quality treatment. The Forum has been organised by the Desiderata Institute since 2011. Each Forum produces a List of Proposals that may improve the treatment within the public health system of children and teenagers with cancer.

NUMBERS IN 2017



20 MONTHS
OF PREPARATION,
JOINT MEETINGS
AND EXPERIENCE GATHERING



48 HOURS OF EXCLUSIVE CONTENT

21 MEMBERS IN THE
ORGANIZING COMMITTEE



1 RECOMENDATION LETTER
TO IMPROVE THE TREATMENT NETWORK



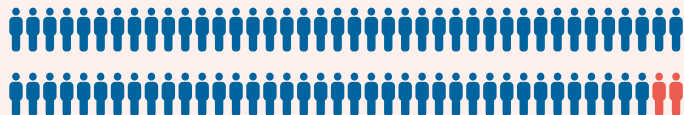
17 TOPICS

SPECIFICALLY ADDRESSED
IN **WORKING GROUPS**,
PRESENTATIONS, **COURSES**,
WORKSHOPS AND **MEETINGS**

485 PARTICIPANTS
IN **THREE DAYS**

3 DAYS

OF ACTIVITIES IN
VARIOUS POINTS
OF **RIO DE JANEIRO**



58 NATIONAL
SPEAKERS

2 INTERNATIONAL
SPEAKERS

Event activities





FORUM ACTIVITIES





18TH SEPTEMBER WORKGROUPS

WG 1 | Access To Treatment Of Childhood Cancer

To contribute to the elaboration of a proposal for integral attention to childhood cancer: regulation, reference and counter-reference and patient care.

COORDINATORS

Sima Ferman | *Chief of the Pediatric Oncology Section of the National Cancer Institute*

Fernando Werneck | *Pediatric Oncohematologist doctor of the Hospital Estadual da Criança*

WG 2 | Childhood Cancer And Professional Training

Discussion on including childhood cancer in the medicine and nursing curriculum and continued education of residents and professionals.

COORDINATORS

Carmen Elia | *Responsible teacher for Extension Projects and Academic Leagues – Estácio de Sá University*

Ana Lygia | *Director of Professional Practices of the Brazilian Nursing Association (ABEN-SP)*

Paulo Peres | *Municipal Health Secretariat – Rio*



WG 3 | Information On Health

Discussion on the challenges to consolidate the implementation of Hospital-based Cancer Registry (HBCR) and Population-Based Cancer Registry (PBCR) in Rio de Janeiro and definition of strategies to monitor and disseminate information considering State Plan for Oncological Care.

COORDINATORS

Marceli Santos | *Supervisor of Cancer Control Programs at the National Cancer Institute*
Rejane Reis | *Cancer Foundation*

WG 4 | Unified Health System Basic Principles Related To Childhood Cancer

Discuss the challenges of implantation and development of palliative care in pediatric oncology services.

Coordinators

Juliana Mattos | *Psychologist at the Federal Hospital of State Servants*
Juliana Lyra | *Social Assistant at the Federal Hospital of State Servants*
Renata Barros | *Doctor at the Federal Hospital of State Servants*
Thais Nery | *Nurse at the Federal Hospital of State Servants*

Opening Ceremony of the 4th Forum

PRESIDING TABLE

Instituto Desiderata, Ronald McDonald Institute, Municipal Secretariat for Health, State Secretariat for Health, National Cancer Institute (INCA).

SPEAKER

Raul Ribeiro | *Raul Ribeiro St. Jude's Hospital (Cure 4Kids)*



19TH SEPTEMBER

ACADEMIC PROGRAM

ROUNDTABLE 1 | What epidemiological information is available about Pediatric Oncology?

Speakers will present information about incidence, morbidity and mortality of child cancer in both national and international contexts.

SPEAKERS

Karina Ribeiro | *Epidemiologist, Cancer Centre Foundation of São Paulo (FOSP)*
Eva Steliavora | *Researcher into epidemiology, International Agency for Research on Cancer (IARC)*
Marceli Santos | *INCA*

CHAIR

Berenice Navarro | *State Secretariat for Health, Minas Gerais*

ROUNDTABLE 2 | Using technology to improve communication and information dissemination about cancer care

How technology has been (and can be) used to strengthen and improve communication, registration, and the monitoring of information about the diagnosis and treatment of child and teenage cancer.

SPEAKERS

Raul Ribeiro | *St. Jude's Hospital (Cure 4Kids)*
Simone Mozzilli | *President President, Beaba NGO*
Marcelo Zuffo | *Chair Professor, Laboratory of Integrable Systems, Polytech of Engineering and Electronic Systems, University of São Paulo (USP)*
Joaquim Caetano de Aguirre Neto



ROUNDTABLE 3 | Situational Diagnosis of Child Cancer Treatment

The presentation will cover the treatment of child cancer in Brazil, Latin American, and other developing countries. Consideration will be given to progress achieved as well as challenges still to be faced in order to make the possibility of cancer cure equally available in the different national contexts. The key question is: how can we achieve equal opportunity in the different national contexts during times of economic recession and the consequent shrinkage in public health systems?

SPEAKERS

Carlos Rodrigues Galindo | *Director, St. Jude's Hospital International Outreach Program*
Teresa Cristina Cardoso | *President, Brazilian Society for Pediatric Oncology*

CHAIR

Alejandro Arancibia | *Medical Coordinator, ICI – Child Cancer Institute – Porto Alegre*

ROUNDTABLE 4 | Socioeconomic impact and support networks for families during child cancer treatment

This roundtable will cover the principal socioeconomic questions that affect treatment and also the governmental and non-governmental resources available to families.

SPEAKERS

Rilder Campos | *President, National Confederation of Care and Support Institutions for Children and Teenagers with Cancer*
Andréa Baptista da Silva Correa | *Superintendent at Management of the Single System of Social Welfare*
Vera Sodr e | *Social Worker at the National Institute for Social Security*

CHAIR

Erika Schreider | *Head of Social services, INCA*

CLOSING SESSION | Monitoring Child Cancer Treatment

CHAIR

Instituto Desiderata



20TH SEPTEMBER

COURSES, WORKSHOPS AND MEETINGS

Health Observatories: Information is Health

This gathering will allow for discussion of the progress and challenges identified by health observatories, and also a discussion of practical concerns as to how to implant an Observatory for child and teenage cancer.

COORDINATORS

Laurenice Pires | *Health Manager, Instituto Desiderata*
Alejandro Arancibia | *Coordenador Médico do ICI*

SPEAKERS

Isabela Cardoso | *Health Policy Analysis Observatory, Federal University of Bahia (UFBA)*
Karla Emília de Sá Rodrigues | *Observatory for Child and Teenage Health, Federal University of Minas Gerais (UFMG)*
Tiago Cepas | *Cancer Observatory, Brazilian Association for Lymphoma and Leukemia, ABRALÉ*
Adilson Hira | *Brazilian Registry of Cystic Fibrosis (REBRASC), Interdisciplinary Centre for Interactive Technologies Centro -USP*

Advocacy in Health

How civil society and health professionals can unite to influence cancer health policies.

COORDINATORS

Roberta Costa Marques | *Director, Instituto Desiderata*

SPEAKERS

Paula Johns | *Directory at ACT + Saúde*
Ana Paula Rechuan | *Parliamentary front against cancer*
Tiago Matos | *Cancer Guide (Oncoguia)*



Course on Paediatric Oncology, with a focus on the Primary Care multi-professional team

This course examines a number of issues from a multi-professional perspective, including epidemiology, the signs and symptoms of child cancer, and cancer emergencies at the level of Basic Care. The main focus here will be on how to deal with children and their families in terms of the problems arising from child cancer, particularly with reference to post-treatment follow-up and reintegration of patient and family into the community.

COORDINATORS

Alejandro Arancibia | *Medical Coordinator ICI*

Sima Ferman | *Head of Paediatrics, INCA*

Ana Lygia Melaragno | *Nurse, Santa Marcelina Hospital*

Panel discussion: Patient records as sources of information on health

Based on experiences with the Cancer Hospital Register, a discussion will be held regarding the importance of patient records, and how information from these can be used in the planning and management of hospital services.

COORDINATORS

Sandra Baliza | *Cancer Hospital Register, University Hospital, Federal University of Rio de Janeiro*

Maria Teresa Cravo | *Technical Department, Hospital Surveillance of Cancer, INCA*

Ivo Oliveira | *Technical Department, Hospital Surveillance of Cancer, INCA*

Laurenice Pires | *Health Manager, Instituto Desiderata*

SPEAKERS

Rafael Vargas | *Oncology Clinician, Santa Casa de Porto Alegre*

Sandra Baliza | *Cancer Hospital Register, University Hospital, Federal University of Rio de Janeiro*

Evelyn Santos | *Health Consultant, Instituto Desiderata*

Representantes DVAS/ConPrev/INCA | *Cancer Hospital Registry, INCA*



Palliative care

Family, professionals, and patients in the palliative care environment: challenges to working in the network; bioethical dilemmas.

COORDINATORS

Juliana Mattos | *Psychologist, Federal Hospital for State Employees*

Juliana Lyra | *Social Worker, Federal Hospital for State Employees*

Renata Barros | *Doctor, Federal Hospital for State Employees*

Thais Nery | *Nurse, Federal Hospital for State Employees*

SPEAKER

Alexandre Costa | *Professor de Bioética da Universidade Federal do Rio de Janeiro*

Meeting of pediatric oncology hospital staff

Discuss the challenges of guaranteeing access to education for hospitalized children and teenagers.

COORDINATORS

Claudia Pires | *Hemorio*

Elizabeth Leitão | *Jesus Municipal Hospital*

Eneida Simões da Fonseca | *Faculty of Education, State University of Rio de Janeiro*

Laurenice Pires | *Health Manager, Instituto Desiderata*

Coming Soon | *Instituto Helena Antipoff*

Rosane Santos | *National Institute of Cancer*



Meeting of Cancer Support Hospices

Discussion about the role of Support Homes for patients and their families during the treatment of cancer. Opportunities and restrictions on working on the network.

COORDINATORS

Cristiane Teixeira | *St. Vincent de Paul Support Hostel*
Keila Pires | *Ronald McDonald Support Hostel*
Luciana Alcantara | *Pediatric Social Services, INCA*
Roberta Nóbrega | *Santa Teresa Support Hostel*

Workshop on the diagnosis of retinoblastoma

Increase the detection of suspect cases of retinoblastoma and improve patient access to diagnosis and treatment from the pediatric oncology services.

COORDINATORS

Clarissa Matosinho | *Ocular Oncologist, INCA*
Nathalia Grigorovski | *Pediatric Oncologist, INCA*

SPEAKERS

Andrea Zin | *Founder, Catarata Child Institute*
Anna Claudia Evangelista | *Geneticista do INCA*
Guillermo Chantada | *Oncologista Pediátrico do Hospital San Juan de Deu (Barcelona) e Hospital Austral (Argentina)*
Celia Antoneli | *Universidade de Santo Amaro*

EXECUTIVE SUMMARY



THE 4TH RIO DE JANEIRO FORUM ON CHILD CANCER is a space of reference to debate and, mainly, consolidate proposals to improve the health care network of childhood cancer. In addition to lectures, courses and meetings, the working groups discuss and recommend actions necessary for the advancement of pediatric oncology in the state of Rio de Janeiro. In the matter, there are issues such as access to treatment, professional training, health information, humanization, etc.

Since the last edition of FPO, in 2015, we recorded advances such as higher number of hospital that perform the hospital-based cancer registry (HBCR), expansion of professional training to early detection in all municipalities of the Metropolitan area and another child-friendly hospital environment is set, this time at INCA, placing Rio de Janeiro in the vanguard regarding the setting of hospital spaces designed for children and adolescents with cancer.

This executive summary compiles the various debates and topics addressed in the three days of the Forum on child cancer, held from September 18th to 20th, 2017, generated recommendations for actions that can transform the childhood cancer scenario in the state and will be monitored for the next two years until the next Forum.

For a child or adolescent with suspected cancer to have quick access to treatment, it is necessary that the health professionals are alert to the disease signs and symptoms, the referral flow for the diagnostic investigation in the hospitals to be known by such professionals and immediate vacancy in the specialized center is available. Ensuring that the mentioned access happens on time depends on many variables. To increase the analysis of suspicions, it is fundamental to increase the training for signs and symptoms throughout the state. Currently, 11% of the family health teams in the state of Rio de Janeiro have been trained. Rio de Janeiro is expanding the training of Primary Care professionals to other municipalities in the state, in partnership with civil society organizations and the State Health Secretariat. In this Forum it was emphasized the importance of the rapid and correct diagnosis of retinoblastoma, influencing the chances of healing such type of tumor, and demanded the creation of more training and better specific referral flows.

Regarding the access to outpatient vacancies, only four of the seven hospitals qualified to treat pediatric oncology in the state have vacancies regulated by the State Regulation System and follow a specific referral protocol. In addition to allow equal access to vacancies, the regulation system also promotes better case follow-up. The absence of an alert signal in electronic medical records, as well as integrated medical records, makes it difficult to follow up patients who have already undergone other medical appointments, bringing rework and repetition of exams and causing loss of time and resources of the Brazilian Unified Health System (SUS). For all children to have equal access to outpatient beds and treatment through regulation, it is necessary to know the real demand and the offer of places in the specialized centers in the state, to define specific protocols of access and to build processes that are transparent and capable of social control.

The more and better information are produced on the different types of cancer that affect children and teenagers and the socioeconomic impacts of treatment, the better policies and actions to increase chances of healing will be defined. Hospital-based Cancer Registries (HBCR), Population-based Cancer Registries (PBCR) and mortality data are the most important basis for knowing the reality of pediatric oncology. Despite the progressive number of hospitals enabled with such registration, Rio de Janeiro still does not have a Population-based Cancer Registry, and it is necessary to overcome the challenge of data quality, according to the international standards, fundamental to integrate studies and global analysis, as the latest published by the International Agency for Research on Cancer (IARC). The constant analysis of published data in the system and the production of monitoring reports with constant exchange between who inserts the information and who analyzes them are fundamental to allow necessary adjustments throughout the process, guaranteeing more reliable data according to the reality of services.

The structure and functioning of medical records in hospitals also influence their quality. The panel on medical records pointed to the need of increasing the visibility and use of available information in HBCRSyS (Hospital-Based Cancer Registry System), to optimize the registrar's working process in the units routines, to engage the clinical staff for the adequate filling of medical records, to stimulate participation in research and to decrease the turnover of registrars.

To support overcoming the challenges on information about pediatric oncology, it was discussed the need of implementing a Child and Adolescent with Cancer Health Observatory which aims to gather, produce and disclose information on pediatric oncology, regarding evidences as ground to make decisions. The health observatories participating in this meeting presented their advances and challenges related to communication, financing and autonomy to produce and publish technical content.

Technology has been debated in its various forms and uses, all central to optimizing and transforming complex systems, such as health ones. Technological contributions can facilitate patients and health professionals routines, enhancing the use of resources and generating savings for individuals and governments. It allows the knowledge exchange, second opinion for diagnoses and collective studies that can be carried out without great technological investment and with enormous technical-intellectual gain. Cooperative groups are also a powerful form of technology based on the exchange of information and the collective construction of knowledge, contributing to the standardization of patient care and the strengthening of work among professionals from different services and cities. Technology can also favor verbal and written communication, hosting patients and their families and humanizing relationships.

Social, economic and political differences in the world impose different opportunities for children and adolescents. To the survival of the young patients, the place where they were born is determinant, and it is not different in Brazil. The regional forums, conducted by the Brazilian Society of Pediatric Oncology (SOBOPE), show a situational diagnosis of childhood cancer and have recorded differences in the Unified Health System, as well as propose local actions to try to standardize treatment in the country. To address these challenges, international organizations such as St Jude Children's Research Hospital have stimulated collaborative work and the creation and strengthening of cooperative groups with a cross-disciplinary approach among countries, reducing drop-out rates and increasing the overall survival rate.

There is a consensus that for the treatment of cancer to succeed, a complex network involving health, care, welfare, legal counseling, among others, is necessary. Depending on the socioeconomic status of the patient and the family, this support will need to be more complete so they can adhere to the treatment and perform it properly. In this scenario, homes and support institutions are critical, as most patients live far from treatment centers. In the state of Rio de Janeiro, there are three support houses, all located in the city of Rio de Janeiro. To enhance this work, it is fundamental to broaden the articulation between the social services of the qualified hospitals and the support houses. Likewise, it is very important to guarantee access to social benefits, especially in times of social and economic retraction. The right to study during treatment is also part of this safety net. The hospital class allows the hospitalized child to study and return to the original school without prejudice to the learning process. Although guaranteed by law, many education professionals, principals and pedagogical coordinators do not know what hospital classes are and how they work. It is necessary closer work and partnership between the health and education departments so that all children and adolescents have the right to education, even if they are hospitalized.

In addition to the network of protection and support, it is also crucial to bring together more people and organizations to influence public cancer policies, since many of the key issues for pediatric cancer are also of extreme relevance for adult cancer such as transparency of the State Plan for Cancer Care, qualification and use of the Hospital-based Cancer Registry (HBCR) and implementation of the Population-based Cancer Registry (PBCR). *Advocacy* is a set of planned and integrated actions that can sensitize and influence managers and policy makers. Increasingly, local action needs to be articulated to global advocacy, as global resolutions have a strong influence on local government decisions. The forum debated this topic for the first time and will continue to articulate with other discussion forums, such as those led by SOBOPE, to mobilize more and more people and organizations involved in cancer control agenda.

Some indications of the working groups that compose the Letter of Recommendations and that will be monitored until the next forum are: conducting a study on the demand and supply of vacancies in specialized centers, organizing the regulatory flow of child and adolescent with suspected cancer cases in the entire state of Rio de Janeiro and the creation of a continuous working group to discuss possibilities of embracing pediatric oncology in undergraduate and continuing education. It is also included in the document, sent to health managers, recom-



recommendations on the implementation and dissemination of The State Plan for Cancer Care, proper monitoring of data in the Hospital-based Cancer Registry, definition of specific information on pediatric oncology in the record files and stimulating the creation of committees of pediatric palliative care in qualified hospitals and the production of materials for family counseling.

Among all these subjects discussed and the recommendations elaborated over three days, four working groups, five lecture tables and nine courses and meetings, cross-cutting and central aspects to overcome the challenges and increase the chances of healing in Rio de Janeiro deserve attention:

Information and transparency - the qualification and use of the Hospital-based Cancer Registry (HBCR) and the implantation of the Population-based Cancer Registry (PBCR) in our state are central. Without these documents, it will not be possible to know the care profile, the real demand for hospital beds and the detailed provision of public services, neither to guide investments and ensure the implementation of the State Plan for Cancer Care, as well as its monitoring.

Collaboration and networking - The challenges posed to childhood cancer in Rio de Janeiro are complex and depend on the articulated and integrated work of municipal, state and federal governments, as well as the active participation of academic and social organizations. This demands an integrated and patient-focused agenda.

The 4th Rio de Janeiro Forum on Child Cancer debates and point out advances and accumulated knowledge built collectively. With this material in hand, we expect managers and health professionals and social organizations to reaffirm and prioritize their engagement to childhood cancer. After all, higher chances of healing depend on the involvement of everyone.

RECOMMENDATION LETTER



WG1: ACCESS TO TREATMENT OF CHILDHOOD CANCER



DATE: 09/18

LOCATION: Museu Histórico Nacional (Mal. Âncora Square, n/n - Centro)



COORDINATION:

Sima Ferman | Chief of the Pediatric Oncology Section of the National Cancer Institute

Fernando Werneck | *Pediatric Oncohematologist doctor of the Hospital Estadual da Criança*

SYLLABUS

To contribute to the elaboration of a proposal for integral attention to childhood cancer: regulation, reference and counter-reference and patient care.



PRESENT SITUATION | SCENARIO:

For a child or adolescent with suspected cancer to have quick access to treatment, it is necessary that the health professionals are alert to the disease's signs and symptoms, the referral flow for the diagnostic investigation in the hospitals to be known by such professionals and the vacancy in the specialized center to be immediate. Ensuring this access to happen on time depends on many variables. For instance, to broaden the analysis of suspicions, it is essential to increase capacity for signs and symptoms throughout the state. Currently, 11% of the family health teams in the state of Rio de Janeiro have been trained. The municipality of Rio de Janeiro regulates only procedures for diagnostic investigation through the National Regulatory System and the Unidos pela Cura reception card. On the other hand, it is the State Health Secretariat responsibility to regulate the outpatient vacancies through SER (State Regulatory System). Although the REUNI (Unified Central Regulation of Municipalities and State) was created in 2015, regulation still occurs in a fragmented way and practically without regard to pediatric oncology. Currently, from the seven hospitals qualified to treat pediatric oncology in the state, only four have vacancies regulated by SER. The hospitals that do not offer vacancies claim they do not trust the regulatory system efficiency, and have consistently witnessed delays in receiving patients. In addition to allowing equal access to vacancies, the regulation system promotes better case follow-up. Another aspect is that the treatment of adolescents presents problems due to the lack of specific protocols that guide the conduct with this group of patients. Thus, the care is part done along with adults and part in qualified hospitals for pediatric oncology, although it is recommended to be offered and taken in pediatric oncology. Finally, the non-integration of electronic medical records makes difficult to follow up patients who have already undergone other medical appointments, bringing rework and repetition of exams, resulting in loss of time and resources of the Unified Health System (SUS). The migration of electronic records to the E-SUS is already happening, but it is important that there is an alert system after the third appointment of the same patient. For all children to have equal access to outpatient beds and treatment through regulation, it is necessary to know the real demand and the offer of places in the specialized centers in the state, to define specific protocols of access and to build processes that are transparent and capable of social control.

 **OUR GOALS**

 **INDICATORS**

 **RESPONSIBLE ORGANIZATION**

<p>To own a diagnosis on demand and offer of outpatient vacancies to evaluate suspicions and beds for hospitalization.</p>	<p>Diagnosis on demand and offer of outpatient vacancies and hospitalization beds.</p>	<p>State Health Secretariat of RJ Hospital Management Department</p>
<p>To own a regulation of pediatric oncology organized in a collective, transparent and quick way.</p>	<p>Regulation protocol of pediatric oncology for the entire State of Rio de Janeiro validated by pediatric oncologists and published in the Oncology Regulation Policy, according to the State Plan for Oncological Care.</p> <p>The creation of a working group (WG) with governmental and non-govermental organization to implement the regulation and keep monitoring the referral of pediatric cases.</p>	<p>State Health Secretariat of RJ</p>
<p>Inclusion of an alert sign in the E-SUS or another electronic primary care record system for the pediatric patient with a return of three or more appointments, as this is an important warning of childhood cancer.</p>	<p>To have the alert sign implanted in electronic medical records.</p>	<p>State Health Secretariat of RJ Municipal Health Secretariat – Rio.</p>



WG2: CHILDHOOD CANCER AND PROFESSIONAL TRAINING



DATE: 09/18

LOCATION: Museu Histórico Nacional (Mal. Âncora Square, n/n - Centro)



COORDINATION:

Carmen Elia | *Responsible teacher for Extension Projects and Academic Leagues – Estácio de Sá University*

Ana Lygia | *Director of Professional Practices of the Brazilian Nursing Association (ABEN-SP)*

Paulo Peres | *Superintendent of General and Specialized Hospitals. Executive Coordinator of Pediatrics. Municipal Health Secretariat – Rio*

SYLLABUS

Discussion on including childhood cancer in the medicine and nursing curriculum and continued education of residents and professionals.



PRESENT SITUATION | SCENARIO:

Although cancer is the first cause of death due to illness in the age group of 5 to 19 years and early diagnosis is known to be a fundamental action to increase chances of healing, the pediatric oncology theme is not included in the health professionals undergraduate curriculum, especially those of medicine and nursing. In the residencies, there are also few courses that contemplate the subject, stronger in the sessions of clinical discussions, especially in medicine field. The training of health professionals, still focused on Primary Care, must gain strength in order to reach emergency care unit (UPAS), pediatrics and emergency professionals, who are responsible for hosting many children and adolescents in the network. By 2016, 11% of the family health teams implanted were trained. Of the fifteen paediatrics leagues identified in the state of Rio de Janeiro, only one reported to develop activities related to such matter. The inclusion of themes related to childhood cancer signs and symptoms during academic training, as well as for professionals who are working in health, is fundamental to early diagnose and increase chances of cure.

OUR GOALS

Inclusion of oncology pediatric subject within the training spaces of medical and nursing graduations and for professionals on duty.

INDICATORS

To offer a multi-institutional and multiprofessional working group responsible for proposing an educational action plan in pediatric oncology.

To have in the WG at least one participant from the university, the non-governmental organization, the Pediatric Society, the Pediatric Oncology Society, the Municipal and State Health Secretariats, the Academic Leagues and Brazilian Nursing Association (ABEN).

RESPONSIBLE ORGANIZATION

Social Organization/ NGOs
SOPERJ
SOBOPE
Universities
State Health Secretariat of RJ
Municipal Health Secretariat of Rio de Janeiro.

WG3: INFORMATION ON HEALTH



DATE: 09/18

LOCATION: Museu Histórico Nacional (Mal. Âncora Square, n/n - Centro)



COORDINATION:

Marceli Santos | *Supervisor of Cancer Control Programs at the National Cancer Institute*

Rejane Reis | *Cancer Foundation*

SYLLABUS

Discussion on the challenges to consolidate the implementation of Hospital-based Cancer Registry (HBCR) and Population-Based Cancer Registry (PBCR) in Rio de Janeiro and definition of strategies to monitor and disseminate information considering State Plan for Oncological Care.



PRESENT SITUATION | SCENARIO:

The production of information in health is strategic for the knowledge of local and global sanitary and epidemiological realities. In the case of cancer, the Population-based Cancer Registry (PBCR) and the Hospital-based Cancer Registry (HBCR) are two important sources of information. Rio de Janeiro is one of the few Brazilian capitals that does not have the Population-based Cancer Registry. It is worth mentioning the progress achieved in the state with the reactivation of the Angra dos Reis PBCR and the State Plan for Oncological Care goal is to implement such registry in all 9 regions of the state by 2021. Regarding the HBCR, six of the seven qualified hospitals in pediatric oncology of the state of Rio de Janeiro has the record. However, half of the records are outdated in relation to the calendar year indicated in INCA's Prevention and Surveillance Coordination (Official Letter No. 138/2017 - CONPREV / INCA, RJ, 07/04/2017). Although HBCR is an important registry to understand the care offered to patients, there are some difficulties observed related to registration of childhood cancer data, especially regarding staging of the disease and the state of the disease at the end of the first period of treatment. The lack of knowledge about the HBCR, the poor quality of clear and legible record keeping, the high turnover of registrars and the lack of human resources in adequate quantity and time for the effective functioning and implementation of HBCR are some of the points observed as obstacles to improve the quality and timeliness of records.

 **OUR GOALS**

 **INDICATORS**

 **RESPONSIBLE ORGANIZATION**

OUR GOALS	INDICATORS	RESPONSIBLE ORGANIZATION
To disclose publicly the State Plan for Oncological Care.	Publication of the Plan on the State Health Secretariat of RJ website, indicating the evolution in fulfilling the goals.	State Health Secretariat of RJ
100% of hospitals qualified in pediatric oncology with HBCR implanted and updated.	Percentage of hospitals enabled with HBCR implanted.	INCA Federal Hospital of Lagoa Hospital Management Department/ Ministry of Health
To implant PBCR in the city of Rio de Janeiro.	PBCR implanted according to the State Plan for Oncological Care goal.	State Health Secretariat of RJ
To offer specific information on pediatric oncology validated by SOBOPE, included in the HBCRSyS.	Inclusion of variables on pediatric oncology in the HBCRSyS of pediatric oncology-enabled hospitals.	INCA SOBOPE
To have the Observatory implemented.	To have the Observatory working	Social Organization/ NGOs
To know and understand the physical and operational structure of HBCR in all hospitals qualified in pediatric oncology.	Survey on the registrars' profile of registrars and installed capacity of cancer registries.	State Health Secretariat of RJ INCA Social Organization/ NGOs

WG4: UNIFIED HEALTH SYSTEM BASIC PRINCIPLES RELATED TO CHILDHOOD CANCER



DATE: 09/18

LOCATION: SOPERJ (Assembleia St., 10/1.812, Centro)



COORDINATION:

Juliana Mattos | *Psychologist at the Federal Hospital of State Servants*

Juliana Lyra | *Social Assistant at the Federal Hospital of State Servants*

Renata Barros | *Doctor at the Federal Hospital of State Servants*

Thais Nery | *Nurse at the Federal Hospital of State Servants*

SYLLABUS

Discuss the challenges of implantation and development of palliative care in pediatric oncology services.



PRESENT SITUATION | SCENARIO:

The concept of palliative care was defined in 1990 and updated in 2002 by the World Health Organization (WHO). It is a type of care still new in Brazil and permeated by many misunderstandings. It is mistakenly understood by many as a care for “when there is nothing else to do”, linked to terminality and not to “the assistance promoted by a multidisciplinary team that aims to improve the quality of life of the patient and his family in the face of a life-threatening disease by preventing and relieving suffering, early identification, impeccable assessment and treatment of pain and other physical, social, psychological and spiritual symptoms,” as suggested by WHO.

Brazil still does not have qualified human resources in sufficient quantity to ensure adequate palliative care for patients. There are recent specializations in the subject and there is not always investment by the public hospital in professional training. In the vast majority of cases, the professionals invest in their training by their own. Another problem is that services do not always have specific multiprofessional teams, as suggested by WHO, which hinders to structure quality care. In addition, the idea that oncological care is of high complexity responsibility, and not of the entire health care network, hampers the relationship between hospitals and primary care, which is a fundamental part of a palliative care network of quality.

The use of opioid medications and the lack of specific legislation that supports health professionals are other challenges that also need to be overcome so Brazil can improve the results in this type of care, and starts to offer it in an equitable way for all patients affected by life-threatening diseases and not just for oncological patients, as it has been the commonest.

 **OUR GOALS**

 **INDICATORS**

 **RESPONSIBLE ORGANIZATION**

<p>To have palliative care commissions in all hospitals enabled with pediatric oncology service of Rio de Janeiro.</p>	<p>Indication of the need for formal constitution of palliative care commissions in the State Directive for Palliative Care in Oncology, according to the State Plan for Oncological Care.</p> <p>Formalized number of commissions formalized.</p>	<p>Hospitals</p> <p>State Health Secretariat of RJ</p>
<p>To offer an incentive for the training of professionals working with palliative care in pediatric oncology, contemplated in the State Directive for Palliative Care in Oncology, according to the Oncological Care Plan.</p>	<p>Number of Professional with training in palliative care (specialization, update or postgraduate) for pediatric oncology services.</p>	<p>Ministry of Health</p> <p>State Health Secretariat of RJ</p> <p>Municipal Health Secretariat of RJ.</p> <p>Universities</p> <p>Hospitals</p>
<p>To propose palliative care actions to promote the integration of primary and tertiary health care networks contemplated in the State Directives for Palliative Care in Oncology, according to the Oncological Care Plan.</p>	<p>Number of activities on palliative care performed with the participation of professionals from Primary and Tertiary Care.</p>	<p>State Health Secretariat of RJ</p> <p>Municipal Health Secretariat of RJ</p> <p>Hospitals</p>



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