

Dăruiește Aripă Association

Strategic Plan for 2021 -2030

Vision

Our vision is to nurture a society that protects children's wings, so that every child can fulfill one's potential.

Mission

We seek systemic changes within the public healthcare sector, scaled at national level, to offer the best possible chances for a normal, fulfilled life for children with cancer in Romania.

Goals

We catalyze change, and set the direction for public health policies addressed to children with cancer. We provide information, solutions and support for the best decisions, to serve the needs of these children.

Values : Communication, authenticity , consistency, transparency, integrity.

Areas of focus

- Development and integration of health and inter-sectoral services (e.g. social)
- Inform & drive public policies
- Support research
- Empower patients and their families

Strategic objectives (SO)

SO 1- Contribute, design and promote consensus for a National Strategy for Child and Young Adult Cancer Care

SO 2 - Support the alignment of cancer care for Romanian children to the best current international standards for clinical practice

SO 3 - Contribute to the development of quality research and communication on the child cancer ecosystem in Romania, and facilitate international cooperation

Specific objectives

SO 1.1 Provide support to the Romanian Society of Pediatric Hematology and Oncology (SROHP) to document the national child cancer situation via the National Child Cancer Registry (RNCCR)

SO 1.2 Drive the agenda to identify and debate major themes to advance child cancer care among the health professionals community, and all other relevant stakeholders

SO 1.3 Promote integration of widely agreed child cancer priorities within the national regulatory framework for cancer services (e.g. the National Cancer Control Plan, NCCP)

SO 2.1 Initiate and advance open debates within the relevant professional community(-ies) on issues related to child cancer quality of care – based on systematically collected inputs from RNCCR and from other dedicated surveys findings

SO 2.2 Foster a supportive environment for the implementation of best clinical practice standards within Romanian pediatric onco-haematology facilities – emulate initiatives to establish reference centers for the top 5 ICC-3 tumour types (based on ERN-Paedcan model)

SO2.3 Contribute to the set up of a comprehensive network of responsive services to cover children and family needs of care throughout the entire course of disease (including long-term survivorship care) with innovative IT support

SO 3.1 Contribute to the continuous quality development of RNCCR and advocate for a comprehensive networking (bilateral data-flows) with national and international information systems (such as ECIS)

SO 3.2 Support efforts to improve Registry coverage and data use in public communication and research

SWOT Analysis

A. Internal strengths

- Skilled human resources covering a broad spectrum of domains and competencies (leadership, public health policy, communication, marketing, public affairs, clinical expertise, etc)
- Autonomy and political independence (no affiliations to political agendas and financing lines, not subject to bureaucratic constraints typical to government financed entities)
- Level of commitment and resilience, and clarity of mission, keep the organization homeostasis within set performance parameters, even during crisis such as the COVID pandemic, and the Ukraine war

B. Opportunities = collaborations

- Privileged relationship with the professional paediatric oncology community (SROHP and hospitals)
- Consolidated public reputation both in terms of expertise as well as probity
- Open relationships of mutual respect and trust with other NGOs, including those dedicated to the child cancer cause (N.B. we are founding members of the Romanian Coalition for the Cause of Children and Young People with Cancer)
- Internationally engaged with Childhood Cancer International (CCI) and its Europe division

C. Threats = challenges

- Domestic economic and political changes and unpredictability are a constant challenge (e.g. sudden fiscal policy changes)
- High turnover of senior-level figures in public bodies that are critical to our goals (e.g. ministers of health, chairs of the National Health Insurance House, and other stakeholders in the public sector)

- Vulnerability to changes in international policies (e.g. EU legislation, red tape)

D. **Weaknesses** = internal challenges

- Difficulties to synchronize top-expert agendas (mainly for clinical collaborators), and to achieve operational alignment for our complex projects
- Current organizational development challenges /mismatched with the level of strategic engagement (e.g. difficulty to respond and manage all the relationships and requirements arising from our initiatives)
- The evolving nature and scope of our projects may generate potential funding difficulties /discrepancies with the current pattern of income generation (mainly via donations from companies and fund-raising)

Critical actions

- Promote the inclusion of key lines of action for the development of child cancer care into **national policies and regulatory framework**
 - o Co-author of the Paediatric Cancer chapter within the National Cancer Control Plan (NCCP) – to address essential issues such as: fragmentation of care, lack of multidisciplinary cooperation, gaps in access to essential medications, inconsistent/insufficient access to tests and treatments currently recommended by international protocols
 - o Catalyze and channel consensus within the relevant professional communities (mainly paediatric oncology and haematology) for key regulatory items to be included in the primary and secondary legislation implementing the provisions in the NCCP paediatric cancer chapter
 - o Devise and institute processes and procedures for the regular legislative monitoring
- Support improvements in the **quality of care for child cancers**, in all areas of service delivery
 - o Support clinical and non-clinical care providers to improve their professional abilities and knowledge (e.g. scholarships, attendance to international educational events, facilitation of access to and dissemination of relevant international literature and guidelines to the appropriate professional audience, etc)
 - o Emulate and nurture the development of national standards of care, designing and piloting of new services (such as telepractice for children and families outside the hospital) – identify and enrol informants with critical competencies, produce the needed body of documentation and obtain endorsement from relevant stakeholders
 - o Design, pilot and roll out digital tools to support clinical practice, service integration (such as multidisciplinary tumor boards) and research in paediatric oncology and haematology
 - o Contribute to improvements for child cancer continuity of care through models of integrated services such as homecare outreach and enabling local providers to work in teams with hospital-based pediatric oncologists

- Garner key stake-holder support and enrollment to design and pilot model projects for centers of reference, for several tumor types
 - Support professional development and recognition of nursing services in paediatric oncology and haematology via educational programs targeting POH nursing staff
- Enhance the performance and impact of the **National Child Cancer Registry**
 - Develop the skills and capacity for human resources,
 - International review of the Registry performance
 - Improve Registry data usage for policy design
 - Enhance the visibility and communication of critical information regarding child cancer (e.g. publication of regular reports, periodic public dissemination of key data)
 - Promote participation of the Romanian Child Cancer Registry in international cooperation projects
 - Support critical research initiatives based on Registry data : survival surveys, access and utilization of treatment modalities, capture-recapture studies to increase data completeness

Planning cycle(s) – Strategic roadmap 2021-2025 is attached

Monitoring and Evaluation (indicators)

- Regular (quarterly) assessment of the implementation of ongoing projects – to check whether the set milestones have been achieved
- Evaluate results in projects due for completion
- Review planning and assess/adjust (if necessary) initiation of projects due to start during the planning cycle

Resourcing policies

- A gradual diversification of funding sources and policy is needed, with a shift from the current business model to a higher level of competitiveness in order to access funding streams appropriate to the structural /systemic features of our projects(e.g. international cooperation projects, EU and EEA tenders, high-level/longterm flagship CSR project commitments from large corporations)
- Increase in-house capacity to generate income to match the extent of increasing demands, as new projects and activities unfold according to the plan

Review process

- Biennial review by the Management Board of the organization activity and achievements, and their consistency with the delineated strategic objectives
- Regular reflection on the appropriateness of planned actions against current developments in the organization ecosystem (e.g. political, economical), acknowledgement/ integration of critical changes, and subsequent adjustments to the plan.

STRATEGIC ROADMAP 2021 -2025

MILESTONES



		2021				2022				2023				2024				2025							
		Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4				
SO1 Policy	Promote the inclusion of key lines of action for the development of child cancer care into national policies and regulatory framework	Draft NPOH strategy outline		formulate Pediatric section of NCCP				work with RSPOH and stakeholders to develop secondary legislation				advocate and monitor for implementation													
	Endorsed by RSPOH				Accepted by MOH				Accepted by MOH				evaluate implementation status												
SO2 Services	Contribute child cancer continuity of care through models of integrated services	evaluate & adjust Constanta hospital based outreach home & palliative care program in SE Romania				optimize model & prepare Bucharest Institute of Oncology (IOB) pilot for South Romania				pilot IOB enhanced outreach for home and palliative care in Bucharest and 6 adjacent counties				design out-of-hospital care guidelines & training program for rollout				extend model implementation to Fundeni and Marie Curie hospitals				enroll regional hospitals (satellite center candidates) such as Craiova and/or Brasov			
	homecare service scope & goals redefined				service operational								implementation toolkit designed and validated				model assessed and adjusted				concept evaluation & review report presented to RSPOH				
	design customized digital support to Constanta outreach services				expand digital capabilities to accomodate all aspects of child cancer care				pilot integrative digital platform in IOB				pilot platform capabilities to integrate different specialities and locations (i.e tumor board and second opinion)				roll out platform use in Fundeni and Marie Curie				pilot platform capacity to support stallite care and local networks				
	prototype developed and tested				DARA platform ready for testing				optimized version ready				comprehensive evaluation report				DARA running in all Bucharest POH departments				at least 1 additional satellite and 1 local support center provide care via DARA				
													agree on priority tumour site with key SH		gather and consolidate expert team		review clinical requirements (ERN criteria and SIOPE protocols) and solve administrative barriers				assemble and train medical team members, configure and endow the appropriate facility, secure approvals and operational financing from MOH				
													explicit partnership agreement				detailed project approved and funding secured								
									review the competencies list of PHO nursing staff				define envisioned scope of practice of Romanian PHO nursing staff and identify professional needs				agree with key SH on professional nursing roles (in pilot projects)				develop educational program and tools				
													position paper on PHO nursing scope of practice		organize international conference on PHO nursing				PHO nursing training package developed						
SO3 Research	Enhance the performance and impact of the National Child Cancer Registry			Structured registry review by ENCR				operational capability enhancement				optimization of data management and utilization				promote the Registry use as a fundament in child cancer allocative policies				enact registry access to complementary data sources (path reports, DC)					
					report presented to RSPOH				data accepted by ECIS		1st comprehensive report with new data set		automated analytics function developed		Registry based budget items of new pediatric cancer funding program				regular bilateral data flows implemented						
					participation in international research projects (BENCHISTA)																				
SO3 Research	Promote participation of RNCCR in international cooperation projects					DSA signed										submitted data accepted		Research results published							
SO3 Research	Support critical research initiatives	Support critical research initiatives based on Registry data : survival studies, data completeness, access to selected therapies																							
					capture /recapture exploratory study										2nd survival study on the 2014-2017 incidence cohort				regional NW capture-recapture study						