



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**

Paediatric Cancer  
(ERN PaedCan)



**Childhood  
Cancer  
International**

## **Deliverable 2.2**

### **D9: PaSOs**

(Parents and Survivors Organizations)

### **Sub-network Roadmap<sup>1</sup>**



Co-funded by  
the Health Programme  
of the European Union

“The content of this represents the views of the author only and it is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.”

---

<sup>1</sup> In the SGA proposal priority was given to the Brain Tumour sub-network; however as foreseen in the Deliverable Title of the SGA in Annex 1 the roadmap of the PaSOs sub-network became priority.

## Table of contents

1. Introduction.....	3
2. Childhood Cancer International (CCI).....	3
3. CCI Europe .....	4
3.1 Activities of parents.....	5
3.2 Activities of survivors .....	6
3.3 Expectations of survivors/parents towards ERN PaedCan.....	6
3.4 Role, structure and responsibilities of CCI Europe within ERN PaedCan .....	9
3.5 Visualized Roadmap .....	13
4. EURORDIS .....	14
4.1 European Patient Advocacy Groups (ePAGs) and their representatives .....	14
4.1.2 The role of ePAGS and ePAG representatives.....	15
4.2 ePAG representatives for ERN PaedCan.....	16
5. European Standards of Care.....	16
6. CCI Europe national contact points within ERN PaedCan .....	18
7. Time frame .....	22

## **1. Introduction**

It is the goal of the European Reference Network for Paediatric Cancer (ERN PaedCan) to improve outcomes of childhood cancer by reducing the current inequalities in different member states. ERN PaedCan aims to provide paramount requirements for 'Cross-border healthcare' (CBHC) allowing the provision of healthcare to children with cancer in a Member State or other than the Member State of affiliation. Considering the potential burden on families seeking cross border health care, i.e. leaving their cultural and language environment and entering social isolation for treatments that may extend over months, ERN PaedCan intends to establish mechanisms to facilitate movement of information, guidelines and knowledge via cross-border virtual tumour boards and virtual consultation systems rather than patients. High-quality, accessible and cost-effective healthcare for childhood cancer is achieved by strengthening the integration of pre-existing knowledge and expertise, and fostering stronger cooperation between patients/parents/survivors, professionals and healthcare authorities.

Within the ERN PaedCan parents and survivors will on the one hand be represented via CCI resp. CCI Europe and as European Patient Advocacy Group (ePAG) as an initiative of EURORDIS – Rare Diseases Europe.

## **2. Childhood Cancer International (CCI)**

The experience of a child undergoing cancer treatment can be traumatic, distressing and isolating for parents and siblings as well as the patient. The impact on the whole family has been well understood by health professionals for many years, as has, the medical needs of the child, but also the necessity to provide services which look after the emotional and social needs of the family of the child.

Parent support groups have been formed over the past thirty years to provide information and practical, emotional and financial support for families to enable them to cope with the difficulties associated with lengthy treatment – often many miles from home.

Childhood Cancer International (CCI; formerly ICCPO - International Confederation of Childhood Cancer Parent Organizations) was founded in 1994, as an umbrella organization of childhood cancer grassroots and national parent organizations. Today, CCI is the largest patient support organization for childhood cancer. It is a global, parent-driven non-profit that represents 183 parent organizations, childhood cancer survivor associations, childhood cancer support groups, and cancer societies, in 93 countries, across 5 continents.

Recognized world-wide as the body representing children/adolescents with cancer, childhood cancer survivors and their families, CCI works in partnership with international development organizations, policy makers, civil society organizations, health, research and medical professionals.

It seeks to inform and catalyze synergistic, cross-sectoral collaboration towards a) reducing increasing deaths from childhood cancer, b) creating a supportive enabling environment for childhood cancer initiatives, c) advancing the cure for childhood cancer, d) improving equity in access to care and e) transforming the quality of care.

As the voice of the children/adolescents, the survivors and their families, who have endured the childhood cancer journey, CCI advocates for recognizing the rights of children/adolescents with cancer and prioritizing childhood cancer as an integral part of the local, national and global child health and development agenda. It draws attention to the fact that the cost of inaction is enormous while accelerated, concerted and integrated action will have societal impact and life changing gains for present and future generations.

CCI's mission is furthermore to share information and experiences in order to improve access to the best possible treatment & care for children with cancer everywhere in the world. It does this through an international network of parent support groups and survivor networks with the common goal of providing a voice for the needs of children with cancer and their families and advocating for increased awareness of childhood cancer at both a local and international level. By working in partnership with other child cancer organizations, the need for psycho-social care for the children and their families and the long-term issues faced by survivors will be promoted.

It provides a large forum organizing events and opportunities for members to meet and share information, experiences and knowledge with other members so that all can benefit from best practice and innovative ideas. They lobby governments and advocate on behalf of children with cancer, they create an awareness of childhood cancer regionally, develop of parent mentoring and assistance programmes, and parent support groups. They also form a therapeutic alliance with the medical team on improving conditions and services in the ward. Furthermore, they collaborate with other relevant stakeholders, for example with SIOP (The International Society of Paediatric Oncology), the WHO (World Health Organization), UICC (Union for International Cancer Control) and the IBTA (International Brain Tumour Alliance). Finally, they encourage the development of survivor group networks around the world and provide opportunities for these groups to meet and share experiences and knowledge and to start common initiatives.

### **3. CCI Europe**

CCI Europe represents Europe in the CCI global network of childhood cancer parents' and survivors' support groups.

The CCI Europe Regional Committee (formerly PPAC - Parents and Patients Advocacy Committee) was created in 2012, within the framework of the EU project ENCCA (<http://www.encca.eu/>).

CCI Europe works together with the medical and psychosocial professional, academia, researchers, scientists, civil society, private organizations and industry for the same aim, to help children and adolescents with cancer to be cured, with no – or as few as possible – long term health problems / late effects,

- engaging advocacy at local, national and international level for affordable drugs, better treatment modalities, financial / psychosocial support of the patients and their families
- providing numerous opportunities for members to meet and share information, experiences and knowledge with other members
- raising awareness about childhood cancer in the public for better support of children and adolescents with cancer and survivors

- providing education and information about the disease, its treatment and survivorship
- understanding the causes of paediatric cancer and promoting prevention attitudes and health lifestyle wherever possible
- providing assistance and guidance in establishing new childhood cancer groups in Europe

CCI Europe is collaborating with partners such as SIOPE (The European Society for Paediatric Oncology – Memorandum of understanding since September 2015), PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) and EURORDIS (Rare Diseases Europe – Membership of CCI).

### 3.1 Activities of parents

In May 2017 the 8th CCI Europe Regional Conference took place in Rome. CCI Europe took this as an opportunity to provide the community with solid information about the ERN PaedCan and to ask for their expectations.

CCI Europe is recently (further) developing a sub-network, which meets the needs of the ERN PaedCan. The structure is shown in the second image below. CCI Europe will have a mediating role between the coordinator of the ERN PaedCan and the national contact points - Patients' and Parents' groups in Europe. A national contact point must not necessarily be a national umbrella organization but should be in regular contact and should collaborate closely with the other (regional) organizations in the country. Besides it turned out that the individuals being national contact points should bring some desired qualifications and agree with a code of conduct regarding their representation of CCI Europe. Therefore, CCI Europe will work out a "Qualification profile" as well as a "Code of conduct". One main aim of CCI Europe will be to keep the community up to date and disseminate all essential information about any innovations or reforms within the ERN. Furthermore, CCI Europe will provide the coordinator with feedback concerning the ERN, which will be given by the national contact points. CCI Europe will continue its advocacy activities also within the ERN and will try to represent the Patients' and Parents' voice as effectively as possible. CCI Europe will be a contact point for affected children and their families and will incessantly work on being as supportable as possible.

In the sense of development, education, dissemination and networking the ePAG representatives are attending several meetings in the context of the ERN on a regular basis. This includes for example the EURORDIS membership meeting in May 2017 in Budapest, the RD-ACTION & DG Santé Workshop on "How can ERNs generate, appraise and utilize clinical practice guidelines, to enhance the impact of consensus guidelines in national health systems?" in December 2017 in Rome, the ERN PaedCan Neurooncology workshop in January 2018 in Hamburg, the ECRD (European Conference on Rare Diseases & Orphan Products) – including the EURORDIS General Assembly as well as one day ePAG meeting in May 2018 in Vienna, etc..

The next CCI Europe Regional conference will take place from April 13<sup>th</sup> – 15<sup>th</sup> in Lisbon (Portugal). The ERN PaedCan will be one important part of the program. Furthermore, the conference is another possibility to link the Survivors and Parents with EURORDIS, SIOPE and the project manager of the ERN PaedCan and to have fruitful exchanges. There will be a "national contact point meeting" during the conference, where the involved people will, amongst others, discuss their "Qualification profile" as well as a "Code of conduct" (please see above).

## 3.2 Activities of survivors

At the CCI Europe Regional Conference 2017 Survivors from Europe exchanged experiences about different ongoing Survivors' projects in Europe as for example the "Mentoring-Programme" in Austria and the "Back to school programme" in Croatia. They started building a European Survivors Network by establishing a working group for European Survivors. One of the first tasks of this group was to work out their action fields as well as a strategic plan and to set goals, which they did recently during their strategy meeting in December 2017 in Vienna.

Another main topic was the Survivorship Passport and data protection in this regard. It was unanimously agreed that the SUPA is a valuable tool for transition from pediatrics to adult health care and will help facilitate LTFU, as well as that with sharing their data Survivors contribute to better therapies and thus preventing possible late-effects for future patients. But it is important that the SUPA is Survivor's property. Survivors can share it on their own terms. They also can decide to have the SUPA but can decline data usage for research and when to get what kind of information. Therefore, lately the working group provided SIOPE with a clear, official statement about the importance of having the SUPA to support them to get funding and resources and at the same time raising awareness for late-effects and the necessity of long-term follow-up on national and European level. Also, two representatives will be included in SIOPE's SUPA - working group.

ERN PaedCan will also continue to support the work on the survivorship passport, an innovative solution for follow-up and to improve transition into adulthood. The current lack of information on many patients' medical history becomes particularly critical as children become adults or as they move to another country. The survivorship passport closes this gap by provision of relevant information on the medical history of patients who ended a cancer therapy, making survivors and healthcare professionals aware of the potential risks or late effects stemming from the previous disease and treatment received based on appropriate guidelines.

The upcoming CCI Europe Regional Conference in April 2018 will be another occasion for the CCI Europe Survivors network as well as for other Survivors from Europe to meet and further develop their working group.

## 3.3 Expectations of survivors/parents towards ERN PaedCan

Ensuuing to some presentations about the ERN PaedCan at the CCI Europe Regional conference in May 2017 in Rome, by Melanie Brunhofer (project manager of ERN PaedCan at CCRI Vienna) and Luisa Basset (CCI Europe) and Matt Johnson (EURORDIS), the attendees were asked about their expectations regarding the ERN PaedCan, to national contact points and to CCI Europe. The answers build the mission of CCI Europe/the ERN PaedCan ePAG and to a certain extent of the network itself.

### 1) ERN PaedCan – What does it mean for you as a parent/survivor? What are your expectations / wishes?

#### Communication

- Exchange of information
- Reliable data bases

- Providing information about medication
- Two-way communication
- PaSOs and HCP's should be on the same level, as well as parents and survivors amongst themselves

### **Close Collaboration / Well-performing network**

- Connection with other contact points/persons, specialized centres, doctors and countries with the aim to provide the best possible treatment and care all over Europe

### **Treatment & Care**

- Support/collaboration from European level to reach equal opportunities in all EU countries
- Reduce mortality and increase the number of survivors
- Easy access to best treatment across Europe
- Improvement of the treatment of very rare cancers
- Focussing on active treatment and follow-up alike
- Coverage of transition issue
- Psycho-social aspects should be strongly considered
- Doctors of Eastern Europe should be advised in pain management
- Better access and expertise for pain management / palliative care
- Availability of experts in the shortest possible time
- Highly specialized doctors better distributed throughout the nation
- Each hospital should have a project manager for this project
- Solving regulation problem (e.g. availability of medication and reimbursement)

### **Cross border health care (CBHC)**

- Help for patients from other countries/cross border cooperation
- Expertise should travel, not patients: At the moment families must organize themselves – logistically and financially - if they have to go abroad
- Legal aspect: Facilitation of transfers within Europe
- It's an efficient way to receive specific cure without the need to move/to avoid the stress caused from it
- It's an efficient way to save time
- It helps under a psychological point of view because it reduces uncertainty

### **Financial and logistic issues**

- Children with lower social status/background should have same access to treatment (How to travel, where to sleep/even for the child if allowed to get out of the hospital for a brief time)
- Financial aspect: Better cost coverage
- Logistic aspect: Include logistic considerations (housing, etc.)

## **2) What are your expectations / wishes to a national contact point?**

### **Information / Knowledge sharing**

- Easy access to information about ERN on a national level
- Transfer of knowledge and latest information
- Information = Right of the patients/parents
- There should be a national network sharing information up- and downwards - also on a national level
- Providing forums for exchange
- Answer to the following question: Where to go with specific illnesses?

### **Close collaboration / Network**

- Organization of meetings of national coordinators
- Improvement of collaboration between organizations
- Defining structures, roles and tasks of national contact points  
-> To cooperate with regional/local organizations in a proper way

### **Other**

- Proactivity
- Advocacy
- Enthusiasm
- Benchmark
- Full support to get more power at national level

## **3) What are your expectations / wishes to CCI Europe?**

### **Information / Knowledge sharing**

- Source of information
- Providing network with basis information / news / updates
- Sharing best practices
- Sharing failures
- Share any information about ERN to make people to benefit asap
- Guaranteed information flow to local organizations via national contact points

### **Inclusion**

- Possibility to give feedback
- Being included in all meetings, forums and activities
- CCI Europe as hub between PaSOs and other stakeholders

### **Network**

- Help to create better partnerships between countries
- Create more cohesion and collaboration amongst survivors

### **Advocacy**



- Work to realize all above (for example share info about parents houses close to hospitals and other specifications)
- Push for the realization of this project

#### **Other**

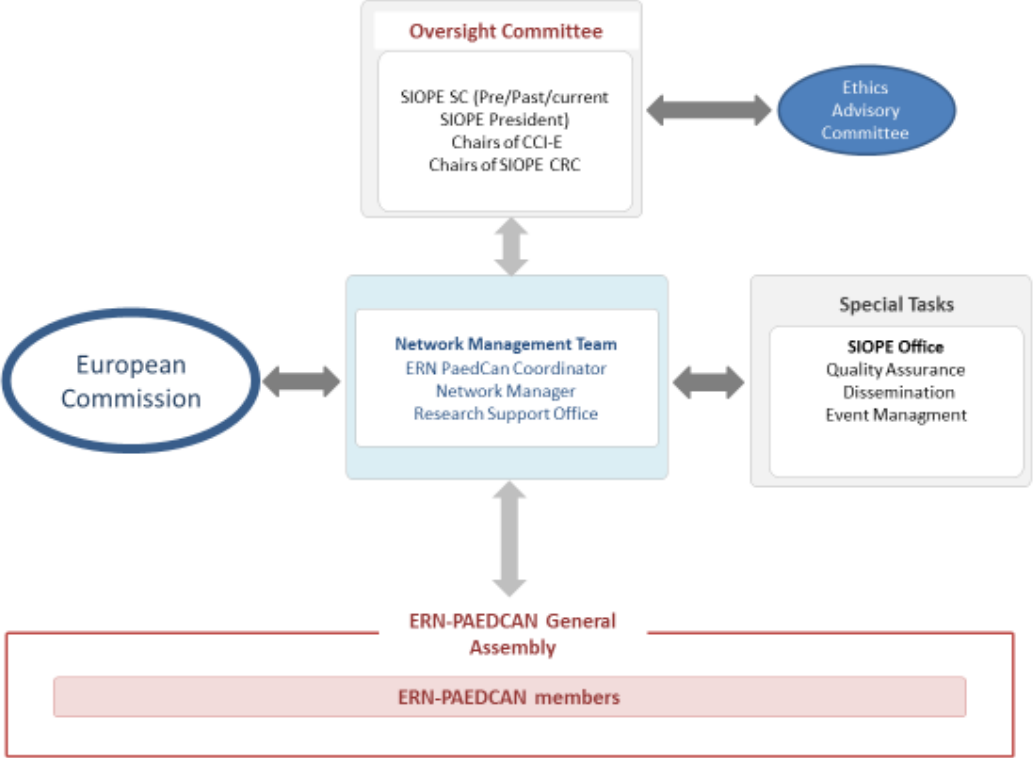
- Proactivity
- Advocacy
- Enthusiasm

### **3.4 Role, structure and responsibilities of CCI Europe within ERN PaedCan**

CCI representatives were already involved as full partners in the ENCCA and ExPO-r-Net projects and will be even more involved in the ERN PaedCan. The CCI (Europe) & ePAG representatives for ERN PaedCan are Anita Kienesberger, Stephanie Schremmer, Luisa Basset and Lejla Kamerić. They are part of the oversight committee of the network and so part of its decision-making structure by providing the views of parents and survivors. Furthermore, they will be involved in the evaluation of the network at regular intervals and contribute to the dissemination of patient information, policy, good practice, care pathways and guidelines in close cooperation with SIOPE. Also, information for parents and childhood cancer survivors will be improved in cooperation with Childhood Cancer International (CCI), including information on clinical trials and clinical research.

CCI Europe has a mediating role between the project coordinator and the affected families, regarding the transfer and provision of information – in both directions, bottom-up and bottom-down. The needs of affected families must reach the network's coordinator and the recent developments must reach the involved childhood cancer organizations.

# Organizational structure



... significantly involved in (further) development



... fitted with decision-making authority



Central points of contact for affected families

„Safety net“ at home and when necessary also abroad

Providing „certainty through transparency“

Providing information about existence and value of ERN

Making aware of patient rights (e.g. right to 2<sup>nd</sup> opinion)



Mediating role

Project coordinator

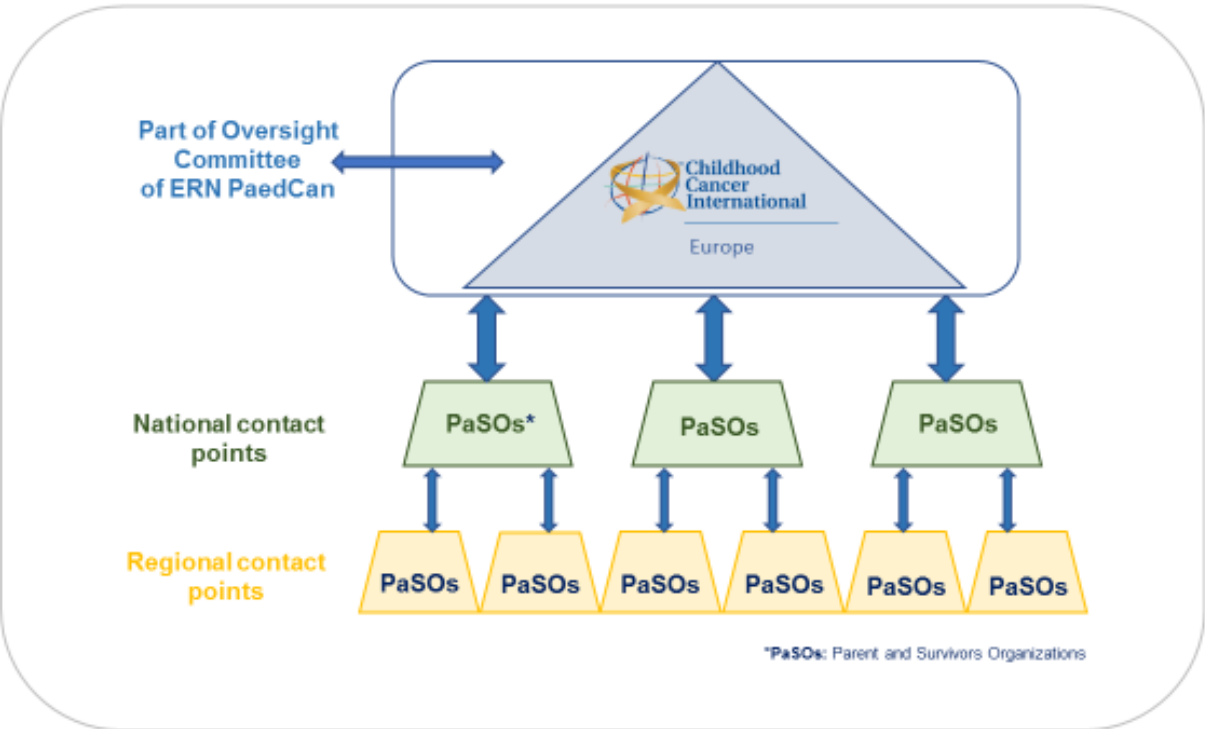
CCI Europe

Affected families / CCI Europe members

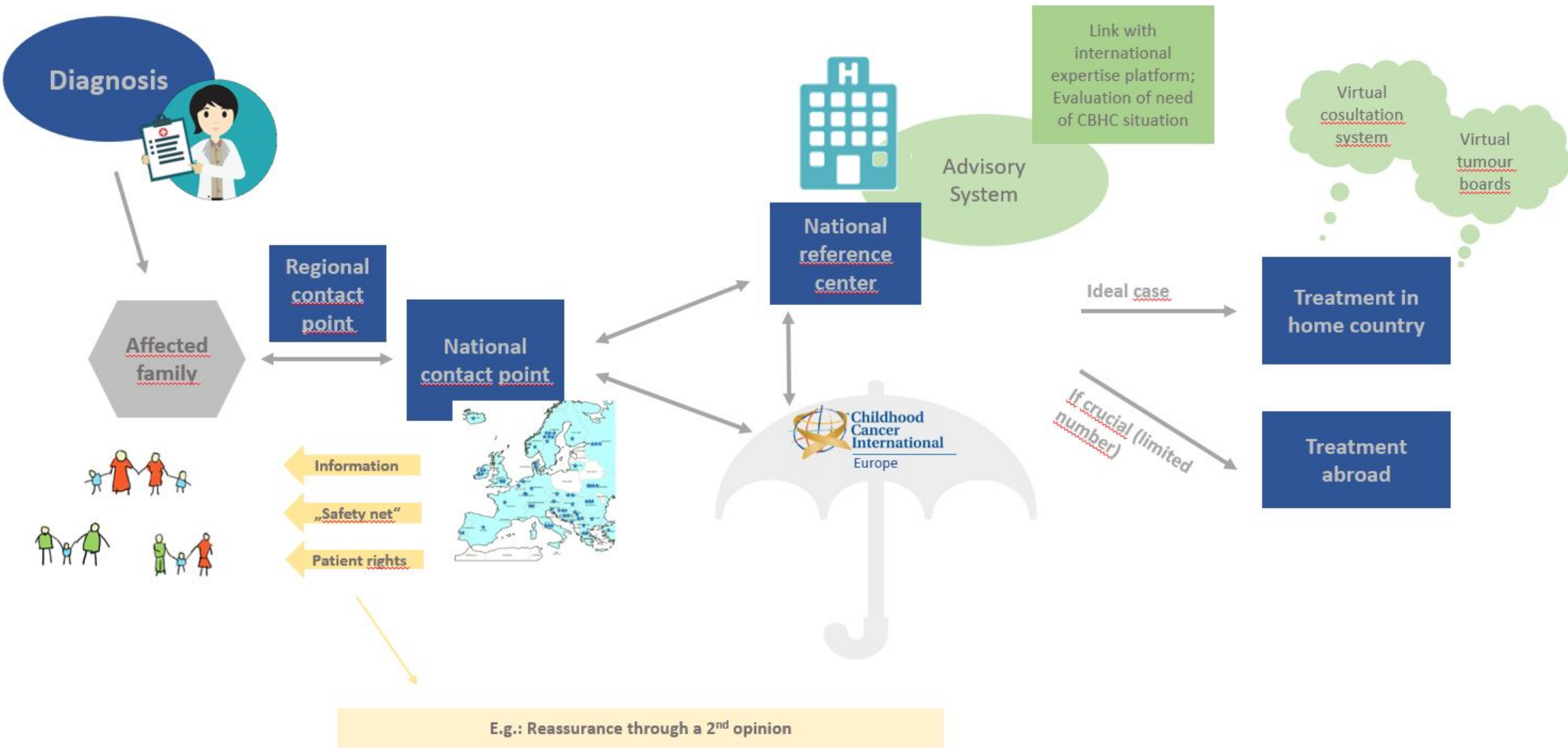
Bottom-up ↑

↓ Bottom-down

In each of the Member States must be a central national contact point available for affected families, whom they can address with their queries, requests and possible uncertainties for advice and support. The duty of the involved childhood cancer organizations is, to inform about the ERN PaedCan itself and its values but at the same time about patient rights /e.g. the right of a 2nd opinion. Providing safety through transparency, is the idea. Affected families have to know, which is the reference center in their country, where to find the needed expertise and best treatment for their child. If a treatment abroad should be unavoidable, then there has to be as well a contact point for the families arriving, to support them regarding logistics, administrative issues, to catch them up mentally and provide them with safety.



### 3.5 Visualized Roadmap



## **4. EURORDIS**

EURORDIS-Rare Diseases Europe is a non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

EURORDIS wants patient organizations to participate in European Reference Network (ERN) decision-making processes and is supporting its membership to ensure a democratic process of patient representation.

Regarding paediatric cancers there already exists a broad and well-working network amongst parents and survivors, namely CCI (Europe). Based on one of CCI's mottos, "Together we are stronger", the collaboration with EURORDIS should be fostered within the framework of the ERN PaedCan. Furthermore, EURORDIS focuses on all 24 ERNs, which brings them all together and offers an infrastructure to meet and exchange knowledge, ideas and experiences amongst the different ERNs.

So, EURORDIS has developed a European Patient Advocacy Group (ePAG) for each ERN disease grouping. ePAGs will bring together elected patient representatives and affiliated organisations who will ensure that the patient voice is heard throughout the ERN development process.

It is important that patient representatives and clinicians evolve how they work together in the new system of ERNs. EURORDIS will continue to support patient representatives in developing this approach and in ensuring that they shape the development of ePAGs.

### **4.1 European Patient Advocacy Groups (ePAGs) and their representatives**

As of May 2017, there are over 100 ePAG patient representatives to represent the wider patient community in the development of ERNs. ePAG patient representatives have an official permanent mandate to represent ePAG member organizations. They liaise with these organizations to ensure true and equitable representation of the patient voice by participating in the Board and sub-clinical committees of their respective ERN.

The recruitment of these representatives is ongoing to ensure that patients are fully represented in the governance of each and every ERN. Patient representatives have already been elected to numerous ERNs but additional applications are welcome for all networks.

ePAG patient representatives must come from a patient organization in the EU. ePAG representatives are members in their respective ERN Boards. The role and function of ePAG patient representatives will be agreed with the ERN Network Coordinating Lead.

ePAG representatives must adhere to the EURORDIS Charter of Volunteers. The number of patient representatives per ePAG is determined in collaboration with clinical coordinating teams of ERN applications and according to the scope of the respective ePAG membership.

EURORDIS is also implementing an ePAG leadership capacity-building programme, which will empower ePAG patient representatives with the knowledge and skills they need to be able to effectively participate in ERN activities.

#### 4.1.2 The role of ePAGS and ePAG representatives

Specifically, ePAGs and ePAG representatives:

- Contribute to the ERN Board to provide the perspective of patients on all relevant aspects of the ERN strategy, policy & organizational processes
- Promote and encourage a patient-centric approach in both delivery of clinical care, service improvement and strategic development & decision-making
- Advocate for care that is patient-centered and respectful of patients' rights and choice
- Provide the patient perspective on the application of personal data rules, compliance of information consent & management of complaints
- Ensure that processes to address all ethical issues and concerns for patients are in place, balancing patient and clinical needs appropriately
- Advise on transparency in quality of care, safety standards, clinical outcomes & treatment options
- Advise on overall planning, assessment and evaluation of ERN activities and initiatives
- Monitor the performance of the ERN by reviewing quality indicators such as clinical outcomes of diagnosis and treatment
- Develop an ePAG feedback and evaluation framework across all ERNs to provide patient experience feedback of ERN and healthcare providers' activities
- Monitor and evaluate the adoption of patient feedback by the ERN based on patient experience surveys prioritizing the objectives, work plan and service improvement in the network on an annual basis
- Contribute to the development and dissemination of patient information, policy, good practice, care pathways and guidelines
- Contribute to research e.g. defining research areas important to patients and their families and disseminating research-related information
- Identify expert centers to join the ERN as a full member or affiliated partner
- Provide an evidence-based patient perspective on the needs of people living with a rare disease and ensure all rare diseases are considered and included in ERN discussions and activities
- Produce annual ERN evaluation reports

Collectively, ePAGs represent the perspective and interests of European rare disease patient organizations associated with ERNs.

## 4.2 ePAG representatives for ERN PaedCan

- **Luisa Basset**  
Federación Española de Padres de NIÑOS CON CÁNCER
- **Lejla Kamerić**  
Heart for kids with cancer – Bosnia and Herzegovina
- **Anita Kienesberger**  
Austrian Childhood Cancer Organization
- **Stephanie Schremmer**  
Austrian Childhood Cancer Organization

*CCI Europe Regional Committee*

## 5. European Standards of Care

The reference document for the treatment of children with cancer is the European Standards of Care, which should be ideally implemented in the national cancer plans of each European country. This will remain another objective to be achieved in the framework of the ERN PaedCan accompanied by the EU project JARC (Joint Action on Rare Cancers).

These Standards are the basis for CCI Europe’s work and efforts for better treatment and care for children and adolescents with cancer.

Since 2008, SIOPE led the preparation of a very important document, the ‘European Standards of care for Children with Cancer’. Widely recognised as a reference document to evaluate progress in drug development, treatment and care in the various paediatric cancer treatment centres all over the continent, the Standards of Care suggest the ideal requirements for every centre specialised in the treatment of children with cancer. Developed together with Professor Jerzy Kowalczyk, the Polish Ministry of Health and the Polish “Communication without Barriers Foundation”, this document has been created after a first Europe-wide survey collecting information on the existing national situation of paediatric haemato-oncology wards. In 2009 paediatric oncologists, parent’s organisations and policy-makers attended a high-level conference in Warsaw, where discussions resulted in a first draft of the ‘Standards of Care’ document, integrated thereafter as a deliverable in the ‘European Partnership for Action Against Cancer’ (EPAAC) project, a unique partnership bringing together stakeholders from the entire cancer continuum in Europe to share knowledge and expertise to prevent and control the burden of cancer. A SIOPE survey in the EPAAC framework recently showed that a wide disparity exists in the implementation of these standards of care across different European countries (J. Kowalczyk et al., ‘Towards reducing inequalities: European Standards of Care for Children with Cancer’, EJC, Volume 50, Issue 3, Pages 481-485, February 2014).

The Standards are now available in 19 languages, and a second survey is currently assessing the implementation of its recommendations after 5 years, helping SIOPE to better advocate improvements in the current situation. Highlights from the Standards include:

- Recommended staffing levels for the paediatric haematology/oncology ward
- Components of care in a specialist facility
- Delivery of Therapy
- Monitoring the late outcomes of cancer



- Psychological and Psychosocial Care
- The rights of the hospitalised child
- The critical role of parents

## 6. CCI Europe national contact points within ERN PaedCan

The figure “Integration of parents’ and survivors’ organizations in the ERN PaedCan” in chapter 4 illustrates the way how the integration of parents and survivors in the ERN should work. The following national contact points of parents’/survivors’ organizations are the link between CCI Europe and the local organizations in each country. CCI Europe is the link between the coordinator of the network and the national contact points.

CCI Europe national contact points within the PaedCan ERN			
Organization	Country	Contact Point	
		Name	E-Mail
Österreichische Kinder-Krebs-Hilfe	AUSTRIA	Anita Kienesberger	<a href="mailto:a.kienesberger@kinderkrebshilfe.at">a.kienesberger@kinderkrebshilfe.at</a>
KickCancer	BELGIUM	Delphine Heenen	<a href="mailto:info@kickcancer.org">info@kickcancer.org</a> ; <a href="mailto:delphine@kickcancer.org">delphine@kickcancer.org</a>
Association “Heart for kids with cancer” (Udruženje “Srce za djecu koja boluju od raka”)	BOSNIA & HERZEGOVINA	Lejla Kamerić Harun Šabić	<a href="mailto:lejla.kameric@gmail.com">lejla.kameric@gmail.com</a> ; <a href="mailto:harun.sabic@srcezadjecu.ba">harun.sabic@srcezadjecu.ba</a>
Association Children with Oncohematologic Diseases	BULGARIA	Theodora Armenkova	<a href="mailto:armenkova@gmail.com">armenkova@gmail.com</a> ; <a href="mailto:ohz_deca@abv.bg">ohz_deca@abv.bg</a>



Firefly - Association for helping children and families facing malignant diseases (Krijesnica - Udruga za pomoć djeci i obiteljima suočenim s malignim bolestima)	CROATIA	Mihael Severinac	<a href="mailto:mihael@krijesnica.hr">mihael@krijesnica.hr</a>
Familier med kræftramte børn (FMKB)	DENMARK	Tommy Brøgger	<a href="mailto:info@fmkb.dk">info@fmkb.dk</a>
Estonian Association of Parents of Children with Cancer	ESTONIA	Kaili Lellep	<a href="mailto:info@vahilapsed.ee">info@vahilapsed.ee</a>
SYLVA	FINLAND	Ms Marika Aro (CEO) Dr Antti Karjalainen (Research)	<a href="mailto:sylva@sylva.fi">sylva@sylva.fi</a> ; <a href="mailto:Marika.Aro@sylva.fi">Marika.Aro@sylva.fi</a> ; <a href="mailto:Antti.Karjalainen@sylva.fi">Antti.Karjalainen@sylva.fi</a>
UNAPECLE	FRANCE	Frédéric Arnold	<a href="mailto:contact@unapecle.net">contact@unapecle.net</a>
Monk Andrew's Charity Foundation (CCI members from 2018)	GEORGIA	Miledi (Tinatin) Chkhvimiani	<a href="mailto:monkandrew.fund@gmail.com">monkandrew.fund@gmail.com</a>
Deutsche Kinderkrebsstiftung	GERMANY	Ria Kortum	<a href="mailto:r.kortum@kinderkrebsstiftung.de">r.kortum@kinderkrebsstiftung.de</a>
Floga - Parents association of Children with Cancer	GREECE	Georgia Kokkinou	<a href="mailto:floga@floga.org.gr">floga@floga.org.gr</a>
Childhood Cancer Foundation (CCF (Light it up Gold))	IRELAND	Mary Claire Rennick	<a href="mailto:info@childhoodcancer.ie">info@childhoodcancer.ie</a> ; <a href="mailto:Maryclaire.rennick@childhoodcancer.ie">Maryclaire.rennick@childhoodcancer.ie</a>

Federazione Italiana associazioni Genitori Oncoematologia Pediatrica (FIAGOP)	ITALY	Angelo Ricci	<a href="mailto:presidente@fiagop.it">presidente@fiagop.it</a> ; <a href="mailto:info@fiagop.it">info@fiagop.it</a>
Fondatioun Kriioncobskrank Kanner	LUXEMBOURG	Anne Goeres	<a href="mailto:contact@fondatioun.lu">contact@fondatioun.lu</a>
FENIX MONTENEGRO' NGO' association of parents of children with child's cancer	MONTENEGRO	Dijana Stojanović	<a href="mailto:fenix.crnagora@gmail.com">fenix.crnagora@gmail.com</a>
VOKK	NETHERLANDS	Jaap den Hartogh	<a href="mailto:bureau@vokk.nl">bureau@vokk.nl</a>
ISKIERKA Foundation	POLAND	Magda Stajno	<a href="mailto:m.stajno@fundacjaiskierka.pl">m.stajno@fundacjaiskierka.pl</a>
Acreditar - Association of Parents and Friends of Children with Cancer	PORTUGAL	Telma Sousa	<a href="mailto:ts@acreditar.pt">ts@acreditar.pt</a>
Daruieste Aripi Association (Give Wings Association)	ROMANIA	Alina Pătrăhău	<a href="mailto:alina@daruiestearipi.ro">alina@daruiestearipi.ro</a>
Children and parents against cancer (CAPAC)	RUSSIA	Ekaterina Kiseleva	<a href="mailto:katerinakiss@mail.ru">katerinakiss@mail.ru</a> ; <a href="mailto:info@capac.ru">info@capac.ru</a>
"ZVONČICA" Childhood Cancer Parent Organization	SERBIA	Irina Ban	<a href="mailto:udruzenjezvoncica@gmail.com">udruzenjezvoncica@gmail.com</a>
SMILE, n.o., POMÁHAME S ÚSMEVOM	SLOVAKIA	Ludmila Hurajova	<a href="mailto:hurajova@lifesupport.sk">hurajova@lifesupport.sk</a>
JONATAN PRIJATELJ, Društvo staršev otrok z rakom	SLOVENIA	Tatjana Kruder	<a href="mailto:tatjana.kruder@siol.net">tatjana.kruder@siol.net</a>

Federación Española de Padres del Niños con Cáncer	SPAIN	Luisa Basset	<a href="mailto:LBASSET@mes.upv.es">LBASSET@mes.upv.es</a>
Barncancerfonden	SWEDEN	Holly Wattwil	<a href="mailto:holly.wattwil@gmail.com">holly.wattwil@gmail.com</a>
Zoé4life	SWITZERLAND	Nicole Scobie	<a href="mailto:nicole@zoe4life.org">nicole@zoe4life.org</a>
Tabletochki Charity Foundation	UKRAINE	Yuliya Nogovitsyna	<a href="mailto:info@tabletochki.org">info@tabletochki.org</a>
Childhood Cancer Parents Alliance (CCPA)	UK	Sam Schoolar	<a href="mailto:ro@ccpa.org.uk">ro@ccpa.org.uk</a> ; <a href="mailto:sam@shinealightss.org.uk">sam@shinealightss.org.uk</a>

## 7. Time frame

