

# SIOP EUROPE ANNUAL REPORT



20 YEARS OF PROGRESS  
IN PAEDIATRIC HAEMATO-ONCOLOGY IN EUROPE



SCIENCE  
& EDUCATION



PROJECTS  
& PLATFORMS



GOVERNANCE  
& FINANCIALS



HEALTH  
& WELL-BEING

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# MESSAGE FROM THE PRESIDENT & CEO

## > 20 Years of Progress in Paediatric Haemato-Oncology in Europe

Dear colleagues, members, associates and partners,

We are delighted to present the first Annual Report of the European Society for Paediatric Oncology (SIOPE Europe). This report highlights SIOPE Europe's achievements over the past year (2018) in support of our vision and mission for the next decade: to increase the cure rate and the quality of cure of children with cancer. In our journey to cure childhood cancer through collaboration, advocacy, research, education and communication, we have made substantial progress since SIOPE Europe was established in 1998.

As this report shows, **2018 was an extraordinary year for SIOPE Europe, and one marked by a key milestone – celebrating 20 years of activity and progress in paediatric haemato-oncology in Europe.** Several events took place to mark this 20-year landmark:

- **SIOPE Europe Gold Ribbon Awards**

An awareness-raising event to honour key personalities and organisations dedicated to the paediatric cancer cause: Tuesday 25 September 2018, Vaudeville Theatre, Brussels

- **SIOPE – MAC (MEPs Against Cancer) Event**

'Celebrating 20 Years of Progress in Paediatric Haemato-Oncology in Europe'

Tuesday 25 September 2018, European Parliament, Brussels

- **Run for Kids with Cancer... SIOPE Europe Fintro Dwars door Mechelen**

Sunday 30 September, Mechelen, Belgium)

Further to these achievements in 2018, we also launched the first **SIOPE Europe Annual Meeting**, scheduled to take place on 20-24 May 2019 in Prague, Czech Republic. This multidisciplinary meeting, in partnership with Childhood Cancer International – Europe (CCI-Europe), offers a distinct opportunity for professionals from various fields to share their knowledge and collaborate on cutting-edge research in paediatric haemato-oncology.

Besides the Annual Meeting, we have made significant strides and advancements in many other projects and activities such as the ACCELERATE Platform, ERN PaedCan, PARTNER Project, Survivorship Passport, QUARTET, PRIMAGE, Young SIOPE Group, and much more.

Continued progress against childhood cancer requires collaboration, innovation and stimulation. As outlined in this report, SIOPE Europe meets the challenge of driving innovative childhood cancer knowledge to patient care by pursuing an agenda that is scientifically courageous, far-reaching, inclusive and collaborative.

Powered by the enthusiastic and committed efforts of our 1862 members from 35 European countries, and guided by numerous key influencers in paediatric oncology and haematology, SIOPE Europe will indeed continue transforming knowledge into innovative practice until our mission — the cure of all childhood cancers — is accomplished.

We invite you to read this Annual Report and take stock of the progress the SIOPE Europe community has made as we work towards a brighter future for children and young people with cancer.



**Pamela Kearns**  
SIOPE Europe President



**Samira Essiaf**  
SIOPE Europe CEO

# ABOUT SIOPE EUROPE

The only pan-European organisation representing all professionals working in the field of childhood cancers with the goal to increase the cure rate and the quality of cure of children with cancer by 2025 (SIOPE Strategic Plan, 2015)

## > Strategic Plan

Since the launch of the SIOPE Strategic Plan in September 2015, SIOPE Europe has been steering and coordinating the effective implementation of this plan, together with the European Clinical Trial Groups (ECTGs) and the National Paediatric Haematology Oncology Societies (NAPHOS) in close cooperation with the parents, patients, and survivors' advocates from the Europe Regional Committee of Childhood Cancer International (CCI).

Having established a long-term sustainable Strategic Plan – to increase the cure rate and the quality of survivorship for children and young people with cancer over the next ten years – the ultimate goal is to increase the disease- and late-effect- free survival after 10 years from the disease, and beyond.

SIOPE Europe therefore counts on all stakeholders to beat childhood cancer and achieve more and better cures by 2025.



**The Strategic Plan includes seven medical and scientific objectives to achieve these goals:**



### Innovative treatments

To introduce safe and effective innovative treatments (i.e. new drugs, new technologies) into standard care;



### Teenagers and Young Adults

To address the specific needs of teenagers and young adults (TYA), in cooperation with adult oncology;



### Precision cancer medicine

To use improved risk classification as well as biological characteristics of both the tumour and patient (such as molecular and immunological factors) to help guide decisions on which therapies to use;



### Quality of survivorship

To address the consequences of cancer treatment such as long-term side effects, to better understand the genetic background/risk of an individual, and to improve quality of life of survivors of childhood cancer;



### Tumour biology

To increase knowledge of tumour biology and speed up translation from basic research to clinical care to benefit patients;



### Causes of cancer

To understand the causes of paediatric cancers and to address prevention wherever possible.



### Equal access

To bring about equal access across Europe to standard care (in both diagnosis and treatment), expertise and clinical research;



## > Key Milestones

1998



**1998:** Established as the European branch of SIOPE (International Society of Paediatric Oncology).

2007



**2007:** Became an independent organisation, with a permanent secretariat in Brussels and a professional structure.

2009

**2009:** Succeeded in obtaining an EU-funded grant for the creation of ENCCA, a European Network for Cancer research in Children and Adolescents comprising 34 influential European research institutes.

2011

**2011:** Formerly known as 'ECRC', the SIOPE Clinical Research Council was originally founded within the ENCCA project with the aim of establishing a 'European Virtual Institute' for clinical and translational research in childhood and adolescent cancers.

2012



**2012:** Underwent a second major restructuring, implementing a new membership model thereby opening its membership to national paediatric haemato-oncology societies in Europe.

2015

**2015:** The SIOPE Strategic Plan was officially presented and launched (at the 2015 European Cancer Congress) and at the MEPA Against Cancer' Group event.

2018



**2018:** Marked and celebrated 20<sup>th</sup> Anniversary.



# 20 YEARS OF PROGRESS IN PAEDIATRIC HAEMATO-ONCOLOGY

## > 20<sup>th</sup> Anniversary

While 2018 was a year to honour SIOPE Europe's past with its 20<sup>th</sup> Anniversary celebration, it was also a year for the SIOPE Europe leadership to focus on the strategic vision and the future of paediatric oncology in Europe.



Therefore, 2018 was an opportunity to reflect – to look back on SIOPE Europe's history and take stock of the achievements. It was also an opportunity to highlight where SIOPE Europe – and the European paediatric oncology community as a whole – should amplify efforts to meet current and future challenges across all the objectives as identified in the Strategic Plan. SIOPE Europe marked its 20<sup>th</sup> Anniversary through several events to increase awareness of the organisation and its mission.

## > SIOPE Europe Gold Ribbon Awards – 25 September 2018, Vaudeville Theatre, Brussels

Attended by more than 100 people from diverse fields, the first edition of the SIOPE Europe Gold Ribbon Awards was an outstanding success.

This exceptional event was an occasion to mark SIOPE Europe's 20<sup>th</sup> Anniversary, taking stock of the achievements and highlighting where the European paediatric haemato-oncology community should amplify efforts to meet current and future challenges across all the objectives as defined in the SIOPE Strategic Plan.



The Awards were presented to key influencers of the wider paediatric cancer community – policy-makers, scientists/academics and civil society – for their outstanding contribution to the paediatric cancer cause.

Within the paediatric cancer landscape, all stakeholders working together are fundamental to progress and improvement. It is indeed a privilege that such key personalities from diverse fields are energetically striving for a brighter future for children and young people with cancer in Europe. SIOPE Europe applauds the unflinching efforts and dedication of the Awards recipients to facilitating life-saving healthcare, innovation and research to improve the lives of children and young people with cancer.



A total of 11 Awards were handed out in the following three categories:

## Policy-Makers Awards

- **Vytenis Andriukaitis** (European Commissioner for Health and Food Safety)
- MEP **Elena Gentile** (S&D, IT)
- MEP **Françoise Grossetête** (EPP, FR)
- MEP **Alojz Peterle** (EPP, SL and President of the MEPs Against Cancer Group – MAC)
- Former-MEP **Dame Glenis Willmott** (S&D, UK)

## Civil Society Award

- **Childhood Cancer International – Europe** (CCI Europe)

## SIOP Europe Presidents Awards

- **Andrea Biondi** (SIOP Europe President, 2006-2007)
- **Kathy Pritchard-Jones** (SIOP Europe President, 2008-2009)
- **Ruth Ladenstein** (SIOP Europe President, 2010-2012)
- **Gilles Vassal** (SIOP Europe President, 2013-2015)
- **Martin Schrappe** (SIOP Europe President, 2016-2018)



## SIOP – MAC (MEPs Against Cancer) Group Event: Celebrating 20 years of progress in paediatric haemato-oncology in Europe – 25 September 2018, European Parliament, Brussels

Hosted by MEP Elena Gentile (S&D, IT) and co-hosted by MEP Alojz Peterle (EPP, SL and President of the MAC Group) with the support of the Association of the European Cancer Leagues (ECL), this event was an occasion to thank policy-makers for their commitment to the childhood cancer cause and trace the road towards further progress.



The policy roundtable gathered the principal stakeholders involved in making strides against childhood cancer, including MEP Françoise Grossetête (EPP, FR) from the European Parliament, as well as the European Commission and the European Medicines Agency.



### **Vytenis Andriukaitis, European Commissioner for Health and Food Safety in his video address:**

*“We all share a common goal when it comes to childhood cancers: To provide patients with the best treatment and care, to support the research and development of new cures and therapies, to build a patient-centred approach and support survivorship.”*

While taking stock of the achievements, speakers highlighted the critical unmet needs: more accelerated development of innovative paediatric medicines, sustainability of the European Reference Networks to address inequalities and targeted projects on the specificities of childhood cancer survivorship.



**MEP Elena Gentile (S&D, IT):**

*“Europe has children at its heart. There is the need for accessible cures, cures that are more modern. Children merit the best treatment, care and follow up. We owe it to them.”*



**MEP Alojz Peterle and President of the MAC Group:**

*“In this battle against childhood cancer, we must reduce inequalities in access to standard care, increase innovative therapies for hard-to-treat forms, establish appropriate policy and care solutions for survivors.”*

Achievements made possible by cooperation at the European level over the past years include raising awareness of the unmet needs in paediatric oncology medicine development, the institution of the European Reference Network for Paediatric Oncology (ERN PaedCan), and the development of care models for childhood cancer survivors.



**Pamela Kearns:**

*“Keywords that have been crucial over the past 20 years at SIOP Europe are networking, collaboration & partnership. Such an open, transparent relationship has enabled us to make progress in paediatric oncology.”*

Participants expressed a strong commitment to an ever-stronger vision for paediatric cancer in Europe while moving towards the next European Parliament and Commission terms.

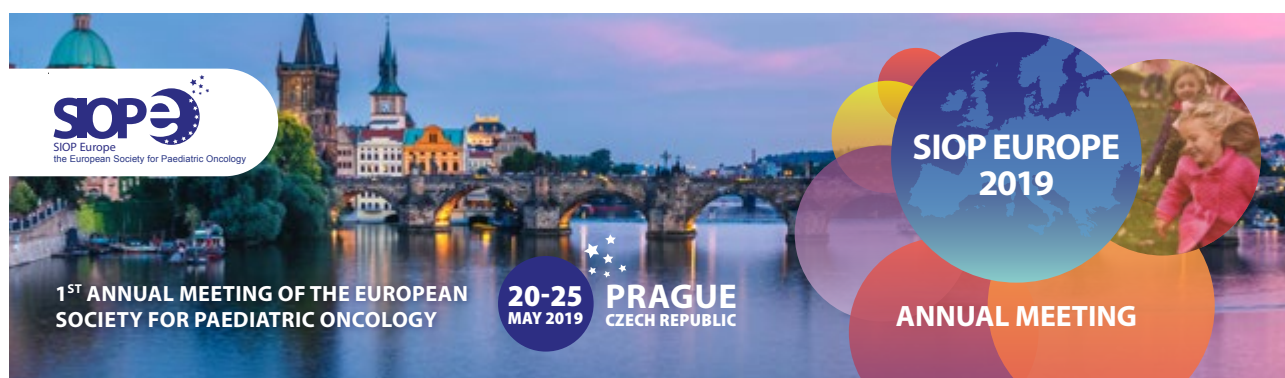




# SCIENCE & EDUCATION

## > SIOP Europe Annual Meeting

The first edition of the **SIOP Europe 2019 Annual Meeting** (20-24 May 2019, Prague, Czech Republic) was launched and promoted to relevant target audiences.



Throughout 2018, SIOP Europe (in partnership with CCI Europe) has promoted this multidisciplinary meeting, which offers a distinct opportunity for professionals from diverse fields to address the main challenges in paediatric oncology and haematology in Europe.

Since this important meeting is per invitation only, all SIOP and SIOP Europe members have received personalised invitations.

More information: [siopeurope.eu](http://siopeurope.eu) Twitter: [#SIOPEurope2019](https://twitter.com/SIOPEurope2019)

## > Methods in Clinical Cancer Research (MCCR) Workshop

Formerly known as the FLIMS Workshop, the Methods in Clinical Cancer Research (MCCR) Workshop is a CME accredited week-long course designed to educate and train early-career investigators in the best practices of clinical trial design and provide access to experienced clinical investigators from different institutions/countries with expertise across all areas of clinical research.

The MCCR Workshop is organised by the European Organisation of Research and Treatment of Cancer (EORTC), European Society for Medical Oncology (ESMO), European CanCer Organisation (ECCO) and American Association for Cancer Research (AACR) and has provided training to over 1600 investigators from all over the world since its' beginning in 1999.

Every year, SIOP Europe has ensured that paediatric oncologists attend this workshop and provides financial support to the selected trainees. In 2018, five paediatric oncologists (from a total of 133) applied for this workshop and four paediatric oncologists took part (total of 80 selected fellows).



### **Jesper Brok, Rigshospitalet (Copenhagen University Hospital):**

*“At the MCCR2018 Workshop, I learned how to fine-tune the protocol specifically for my niche, paediatric oncology, and how to narrow down the protocol to the key elements and keep it simple. Initial ideas about primary outcomes were torn apart and rebuilt more wisely. I was able to improve my knowledge about early phase trials and further develop my protocol draft”.*

## > SIOPE – ESO Masterclass in Paediatric Oncology

The 7<sup>th</sup> SIOPE – ESO Masterclass in Paediatric Oncology took place on 16-21 June 2018 in Berlin, Germany. A total of 47 participants from 20 countries took part.

The biennial SIOPE – ESO Masterclass provides a practice-oriented training with a focus on the application of the most recent research findings to clinical practice. This clinically-oriented educational programme is designed for young paediatric oncologists who wish to improve their skills in clinical management of common childhood tumours. The Masterclass offers a unique learning experience and the teaching sessions focus on applying the latest research discoveries.



European School  
of Oncology



# ONCOPOLICY



## International Childhood Cancer Awareness Day (ICCD2018): 20 February 2018, Brussels

SIOP Europe marked the International Childhood Cancer Awareness Day on 20 February 2018 with its annual event at the European Parliament with the support of MEP Elena Gentile (S&D, IT). The highlight was the call to launch a European Paediatric Cancer Moonshot initiative for the next EU budget.



Academics from SIOP Europe together with parents and survivors made a strong case that the next EU budget for research and health should include paediatric cancer as a clear priority since paediatric cancer remains an important health issue in Europe.

It was noted that the paediatric haematology and oncology community in Europe has made important strides to increase the rate and quality of cure for children and adolescents with cancer, with support from EU projects. Nevertheless, important needs remain and can only be addressed with further international cooperation and support from the EU.



### Pamela Kearns:

*“Lack of coordinated funding for clinical trial activities across Europe is the single greatest challenge. The next EU Framework Programme for research should enable stable and sustainable clinical trial platforms, support international collaborations, and foster funding that can lead to a visionary change for children and adolescents with cancer.”*

Participants from the paediatric haematology oncology community concluded with the call launched by Gilles Vassal, SIOP Europe Board Member: “Towards a paediatric cancer moonshot initiative in the next EU budget –zero deaths, zero sequelae.” Stakeholders recognised the need for sustainable funding to achieve more and better cures for children and adolescents with cancer across Europe.



## > EU Action Plan Paediatrics Medicines Development

On 20 March 2018, the [European Medicines Agency \(EMA\)](#) and the European Commission held a multi-stakeholder workshop focusing on implementation. SIOP Europe and Unite2Cure representatives were official speakers at this meeting, putting the spotlight on the urgent needs and initiatives in the paediatric cancer sector.



SIOP Europe emphasised the Paediatric Strategy Forums jointly implemented by [ACCELERATE](#) and EMA as a model to share information and advance learning in a pre-competitive setting. Other issues that speakers called for included continued public awareness raising, breaking the 18-years dogma for participation in clinical trials, FDA and EMA alignment, earlier submission of Paediatric Investigation Plans, and evaluating the class waiver list.

On 2 October 2018, the EMA and the European Commission's Directorate-General for Health and Food Safety (DG SANTE) published a joint action plan to support the development of medicines for children in Europe.

The report highlighted some important messages that SIOP Europe had been advocating in cooperation with parents, such as the call for multi-stakeholder meetings following the ACCELERATE Platform and its Paediatric Strategy Forum model and action to "establish framework for collaboration of EMA/PDCO with the US FDA's Oncology Center of Excellence Pediatric Oncology Program regarding the assessment of relevant molecular targets in paediatric cancers. To maximise synergies and share expertise in the assessment of relevant molecular targets and to address medical needs with a global perspective."

The action plan provided ground for further multi-stakeholder dialogue and cooperation to accelerate the development of innovative medicines for children with cancer.

## > Joint Action on Rare Cancers (JARC)

The work in the Joint Action on Rare Cancers Work Package 9 – Childhood Cancers was well into its second year.



SIOP Europe in partnership with CCI Europe and other partners have made significant progress on the Tasks of the Work Package, including collecting evidence on the availability of essential medicines for paediatric malignancies across Europe through a national survey to health professionals and parents, formulating recommendations on the organisation of care in paediatric radiation oncology based on existing national guidelines, and mobilising paediatric oncology centres on the topic of access to innovative therapies and clinical trials.

PanCare working with SIOP Europe and CCI Europe coordinated the consolidation of policy recommendations on models of healthcare for childhood cancer survivors. As part of the Task 3, GPOH and the ExpERT Group worked on a manuscript on defining and listing very rare cancers of paediatric age.



# PROJECTS & PLATFORMS



## Overview of EU-funded projects over the years (closed projects)



### SIOPE – EONS Project

Collaboration between doctors and nurses in children's cancer care: Insights from a EU Project

Duration: 2006-2010 (4 Years)



### Oncovideo Project

Standard Practical procedures for young oncologist across EU

Duration: 2010-2012 (2 Years)



### EuroCancerComs

Network for cancer communication in EU connecting different communities involved in the fight against cancer

Duration 2009-2011 (2 Years)



### EPAAC

EU Partnership for Action Against Cancer – WP Standards of Care

Duration: 2009-2014 (5 Years)



### PanCareSurFup

PanCare Childhood & Adolescent Cancer Survivor Care & FU Studies

Duration: 2011-2016 (5 Years)



### ENCCA Project

EU Network for Cancer Research in Children & Adolescents

Duration: 2011-2016 (5 Years)



### ExPO-r-Net

European Expert Paediatric Oncology Reference Network for Diagnostics & Treatment

Duration: 2013-2016 (3 Years)

## > Overview of EU-Projects (ongoing projects)



### **JARC** Joint Action on Rare Cancers

Start Date: November 2016 (Duration: 3 Years)



### **ERN PaedCan** European Reference Network for Pediatric Cancer

Start Date: March 2017 (Duration: 5 Years)



### **PARTNER Project** Paediatric Rare Tumours Network – European Registry

Start Date: November 2018 (Duration: 3 Years)



### **IMI C4C Project** Collaborative Network For European Clinical Trials For Children

Start Date: May 2017 (Duration: 6 Years)



### **Primage** Predictive In-Silico Multiscale Analytics to support cancer personalized diagnosis and prognosis, empowered by imaging biomarkers

Start Date: December 2018 (Duration: 4 Years)

## > Overview Platforms and Projects

### ACCELERATE



#### Multi-stakeholder Platform to improve oncology drug development

**Start date: 2011**

The main objective of ACCELERATE is to create a unique, multi-stakeholder Paediatric Oncology Platform to improve drug development for children and adolescents with cancer in order to:

- Accelerate science driven development of paediatric oncology drugs;
- Facilitate international cooperation and collaboration between all stakeholders;
- Improve early access to new anticancer drugs in development for children and adolescents;
- Set-up long-term follow-up (LTFU) of children and adolescents exposed to new drugs.

### 6<sup>TH</sup> ACCELERATE Paediatric Oncology Conference: 8-9 February 2018, Brussels

Successfully co-organised by SIOP Europe, ITCC and CDDF, the 6<sup>th</sup> edition of the ACCELERATE Paediatric Oncology Conference took place in Brussels on 8-9 February 2018 and was attended by 134 participants.



This annual conference brought together academia, industry, patient advocacy groups and regulators interested in accelerating new oncology drug development for children and adolescents. As a multi-stakeholder platform, it challenges the current ways of working by asking the difficult questions to bring about more effective therapies for children with cancer.

The 6<sup>th</sup> edition of the conference highlighted the urgent need to increase access to innovation for children who most need it. Lessons have been learned from recent successes in paediatric oncology drug development, such as CAR T-cells, larotrecinib and selumetinib.

The changes needed to fostering age inclusive research (FAIR Trials) were also discussed. Since clinical trials that are 'adult-only' hold back young people from getting access to new treatments, FAIR Trials aim to facilitate age inclusive research and propose the age of entry to be reduced to 12 years in adult early phase studies (where medically and scientifically justified). The discussions echoed the need for inclusion of adolescents in adult Phase I to III trials of cancer drugs targeting a relevant disease or mechanism of action, without requiring preceding specific paediatric trials.

Furthermore, the ACCELERATE article 'Joint adolescent–adult early phase clinical trials to improve access to new drugs for adolescents with cancer' was published in *Annals of Oncology* on 1 March 2018. The proposals have been defined within a multi-stakeholder working group with a strong consensus including parent/patient advocates from Unite2Cure. This article advocates for the participation of adolescents with relapsed cancer to early clinical trials running in adult

patients, in order to access new, effective drugs, without the long delays which have been observed over the past 10 years.

The animated exchanges called for the importance of thinking of new ways of developing innovative medicines such as public-private partnerships, new funding systems, etc. Many voiced during the discussions that the ACCELERATE platform provides great hope in changing the current outlook and working together with all the relevant stakeholders is in fact the only way forward to bring more effective and innovative therapies for children with cancer. Change cannot come quickly enough for many children with cancer but the gathering of so many dedicated to changing the existing situation provides great hope.

### 3<sup>RD</sup> Paediatric Strategy Forum: 5-6 September 2018, London

The 3<sup>rd</sup> Paediatric Strategy Forum jointly organised by ACCELERATE and the European Medicines Agency (EMA) took place on 5-6 September 2018 at the EMA in London, UK. The topic of checkpoint inhibitors for use in combination therapy in paediatric patients was discussed.

This forum aims to facilitate dialogue and provide an opportunity for constructive interactions between relevant stakeholders (parents /patients representatives, clinicians, academics, pharmaceutical companies and regulators) on topics requiring an open discussion on the development of medicines in the best interests of children and adolescents with cancer. The goal includes information sharing, in a pre-competitive setting, to facilitate the developments of innovative medicines and ultimately their introduction into the standard-of-care for children with malignancies.

More information here: <https://www.accelerate-platform.eu/paediatric-strategy-forum-4/past-events/paediatric-strategy-forum3/>

### QUARTET (Excellence in Radiotherapy for Children and Adolescents)



- Start date: 2016
- Duration: 5 years

The QUARTET project intends to improve radiotherapy treatments in children and adolescents to reduce the risk of local recurrence and long-term toxicity.

To achieve this, the QUARTET group will investigate and assess the effectiveness of radiotherapy in paediatric cancers through an online prospective quality assurance programme, in partnership with EORTC.

The QUARTET group members held monthly conference calls and met face-to-face in Brussels on 16 October 2018. Throughout the year, the current status of the trials was discussed, as well as plans for the future of the project.

During 2018, the Group has prepared the general treatment protocols of HR-NBL2 (for high risk neuroblastoma) and FaR-RMS (for rhabdomyosarcoma). The group is now finalising the specific radiotherapy quality assurance protocols of these trials, which are both expected to open in the second quarter of 2019.

Up to 1000 patients can be expected to enrol in the next 5-7 years and the QUARTET platform will be used to perform prospective quality assurance.

QUARTET has also played an important role in several other projects and initiatives, such as the Joint Action on Rare Cancers (JARC), by providing input into recommendations on availability of essential therapies for childhood cancers across Europe, including radiotherapy.

The QUARTET group has been approached by several other projects for potential collaboration and is carefully managing these requests to make sure the project keeps focusing on its priority, which is prospective quality assurance.



QUARTET has been funded thanks to the generosity of Fondation Kriibskrank Kanner, a Luxembourg foundation.



## Paediatric Oncology Fellows



Sarah Kelly

After the unsuccessful search for a QUARTET fellow in 2017, the position was re-advertised in January 2018 with a revised job description.

Twenty-four applications were received and 5 shortlisted candidates were selected for an interview. Candidates were interviewed by Prof. Tom Boterberg, Project Coordinator of QUARTET, Dr. Sandrine Marreaud, Head of the EORTC Medical Department and Dr. Mark Gaze, University College Hospital and Great Ormond Street Hospital for Children.

The quality of the applicants was much higher during this second call and two candidates were deemed exceptional, with ample experience with international collaborations, trials and treatment systems. The expertise of the top two candidates is entirely complementary and it was therefore decided that two positions would be offered, one to start in September 2018 (Sarah Kelly) and another to start in early 2019 (Rachel Effeney).

Sarah Kelly started in September and has since been preparing guideline documents as well as guideline templates in order to streamline the process of including the QUARTET platform into upcoming trials. Sarah will simultaneously complete her PhD under the supervision of SIOP Europe Board Member Tom Boterberg at the University of Ghent.

## Survivorship Passport



Stakeholders met in Brussels in September 2018 to discuss the current status and challenges of the Survivorship Passport.

The differences in long-term follow-up in different countries was discussed, as well as standards of care, guideline development, IT infrastructure, funding and implementation plans. CCI Europe, PanCare and SIOP Europe, together with IT partner Cineca plan to form a Steering Committee and a Management Team in order to effectively collaborate on the further development, coordination, implementation and evaluation of the Survivorship Passport Tool.

Earlier this year, the Survivorship Passport group published 'The 'Survivorship Passport' for childhood cancer survivors' in the [European Journal of Cancer](#) (EJC) by Elsevier.

In the meantime, the implementation of the Survivorship Passport in Italy was officially launched during an AIEOP meeting (Italian Association of Paediatric Haematology and Oncology) in February 2018 in Bologna, Italy.

All 53 AIEOP centres in Italy will be able to issue the Survivorship Passport to patients at the end of their treatment. After a successful pilot phase, 275 passports have been issued in 7 centres.

## ERN PaedCan



ERN PaedCan aims help to increase childhood cancer survival and quality of life in the long term by fostering cooperation, research, training and knowledge sharing to end professional isolation, with the ultimate goal of reducing current inequalities in childhood cancer survival and healthcare capabilities across Europe.

### Two ERN PaedCan General Assemblies took place during 2018:

- 1-2 February: 1<sup>st</sup> ERN PaedCan General Assembly, Brussels.
- 25 September: 2<sup>nd</sup> ERN PaedCan General Assembly, Brussels.

Various stakeholders took part in these meetings and provided an update, details on the implementation plan, project performance quality indicators, and the deliverables for Year 2. The participants were engaged in interactive discussions.

SIOPEurope also presented the ERN PaedCan scientific poster 'Saving lives through access to quality care' at the European Conference on Rare Diseases and Orphan Products (ECRD 2018) on 10-12 May 2018 in Vienna, Austria.

Furthermore, on 10 September 2018, EU Commissioner for Health and Food Safety, Vytenis Andriukaitis met with medical experts and people directly affected by childhood cancer at St. Anna Children's Cancer Research Institute in Vienna, Austria.

As the lead on the dissemination of the ERN PaedCan, SIOPEurope wrote and submitted articles in relevant media such as The Parliament Magazine, Government Gazette, Open Access Government, SciTech Europa, bringing further visibility to this project.

Lastly, the Retinoblastoma Webinar for Paediatric Oncologists was released and made accessible online for members of ERN PaedCan.

## conect4children (c4c)



As a member for conect4children (c4c), SIOPEurope shares the goal of improving clinical trial infrastructure to facilitate the development of new drugs for children in Europe.

Comprised of a public-private partnership, c4c is a large collaborative paediatric network facilitating the development of new drugs and other therapies for the entire paediatric population in Europe. The objective of c4c is to accelerate the availability of high-quality scientific data that can improve the safe and effective use of therapies in children.

One of the key goals of the project is to support the use of innovative trial designs and new quantitative methods to foster the development of new innovative medicines and to support development in rare paediatric diseases.

## PARTNER Project



PARTNER is a 3-year long project part of the European Reference Network for Paediatric Cancer (ERN PaedCan). It aims to create a Paediatric Rare Tumour European Registry dedicated to children and adolescents with VRT (Very Rare Tumours) linking existing national registries and to provide a registry for those countries not already having a registry for VRT in place.

### Three PARTNER Project meetings took place during 2018:

- 2 February: Kick-off Meeting, Brussels.
- 17 April: The 1st Consortium Meeting, Luxembourg.
- 14 September 2018: The 2nd Consortium Meeting, Gdańsk.

The strategic value of PARTNER in the field of public health is based on the European wide gathering of information on treatment of VRT and the provision of this information to experts generating new guidance recommendations for daily practice for use by ERN and non-ERN Institutions. The collection of data will contribute to optimised consultation of patients with VRTs. Consequently, experts will increase clinical research and knowledge.

SIOP Europe is leading on the dissemination of the PARTNER Project. Following the project kick-off in February 2018, SIOP Europe created all the communications material such as the logo, brochure, factsheet, poster, website, etc. Furthermore, articles have been published in relevant media outlets such as The Parliament Magazine, SciTech Europa, Open Access Government, including social media visibility.

## PRIMAGE



PRIMAGE (Predictive In-silico Multiscale Analytics to support cancer personalised diaGnosis and prognosis, Empowered by imaging biomarkers) is one of the largest and more ambitious European research projects in medical imaging, artificial intelligence and childhood cancer. The project is devoted to developing methods of computational analysis of medical images applied to childhood cancer.

The PRIMAGE project, financed by the European Commission, kicked off in December 2018. The 16 European partners are participating in the consortium and the project will run for 4 years. The partners are internationally recognised researches active in-silico technologies and clinical experts in paediatric cancer. It is one of the largest and more ambitious European research projects in medical imaging, artificial intelligence and childhood cancer.

The PRIMAGE project proposes a cloud-based platform to support decision making in the clinical management of malignant solid tumours, offering predictive tools to assist diagnosis, prognosis, therapies choice and treatment follow up, based on the use of novel imaging biomarkers, in-silico tumour growth simulation, advanced visualisation of predictions with weighted confidence scores and machine-learning based translation of this knowledge into predictors for the most relevant, disease-specific, clinical end points.

The proposed data infrastructures, imaging biomarkers and models for in-silico medicine research will be validated in the application context of two paediatric cancers, **Neuroblastoma** (the most frequent solid cancer of early childhood) and the **Diffuse Intrinsic Pontine Glioma – DIPG** (the leading cause of brain tumour-related death in children).

SIOP Europe draws on its extensive experience with other European projects to coordinate the dissemination Work Package.

# SIOP EUROPE GROUPS

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## > Young SIOPE Group

In order to support Europe's future paediatric oncologists, a group of young researchers and clinicians began holding regular meetings with the intention of launching a SIOP Europe young oncologists group. A first call for interest received more than 50 responses, presenting an excellent opportunity to discuss opportunities for collaboration. A survey was circulated to gauge interest in the formation of an official group and more than 200 responses were received.

Officially named Young SIOPE, the group's aims include offering a platform for collaboration with the European Clinical Trial Groups, facilitating active participation in the SIOP Europe Annual Meeting and broadening of members' networks.

Young SIOPE will officially be launched at the SIOP Europe 2019 Annual Meeting, where the group has organised several sessions, including joint sessions with other groups, as well as a social event.

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## > SIOP Europe Radiation Oncology Working Group

An initiative, led by QUARTET group members, has been launched to create a European Paediatric Radiation Oncology Working Group, as a real need for a paediatric radiotherapy working group at the European level was identified. This group is expected to broaden the scope and impact of QUARTET. The working group aims to explore the reasons why participation in clinical trials is relatively low and also aims to improve access to high quality radiotherapy for all paediatric patients.

Initially, the focus of the group will be on clinical research, quality control and advocacy. In the future, the group will also discuss how to further develop the QUARTET platform.

The official launch for this Working Group is during the SIOP Europe 2019 Annual Meeting.

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## > SIOP Europe AYA Committee

In early 2018, a small group of physicians dedicated to Adolescent and Young Adult (AYA) cancer issues gathered with the idea to form a SIOP Europe AYA Committee. Over the next several months, meetings were held by telephone conference in order to refine the group's purpose, aims and membership.

The aims of the SIOP Europe AYA Committee are to provide strategic and direction-forming input into existing networks and groups such as ENTYAC and the ESMO/SIOPE AYA Working Group, as well as to liaise with professional and patient organisations to bring AYA issues onto the political agenda.

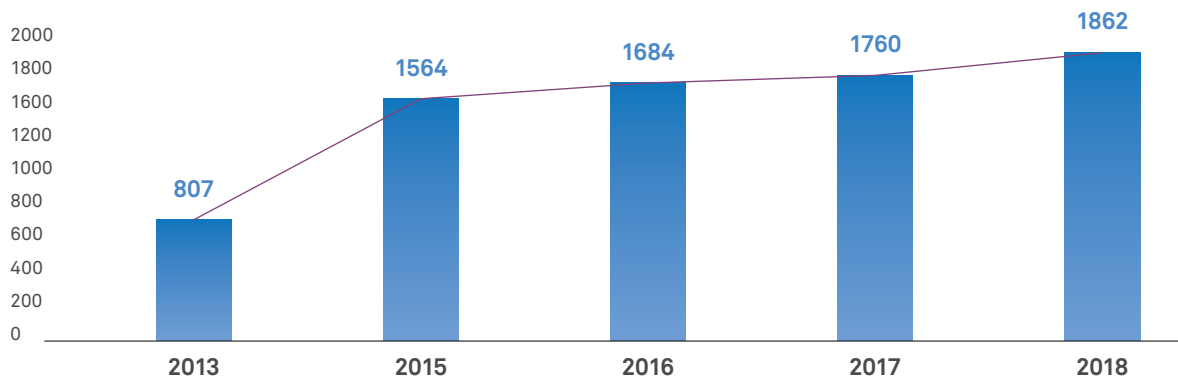
In order to achieve its aims, the committee will consist of a small strategic committee of approximately 8-10 members, ensuring adequate representation of paediatric and adult oncologists, as well as a nurse, while also taking into account the geographical distribution of its members.

The SIOP Europe AYA Committee will officially launch on the occasion of the SIOP Europe 2019 Annual Meeting.

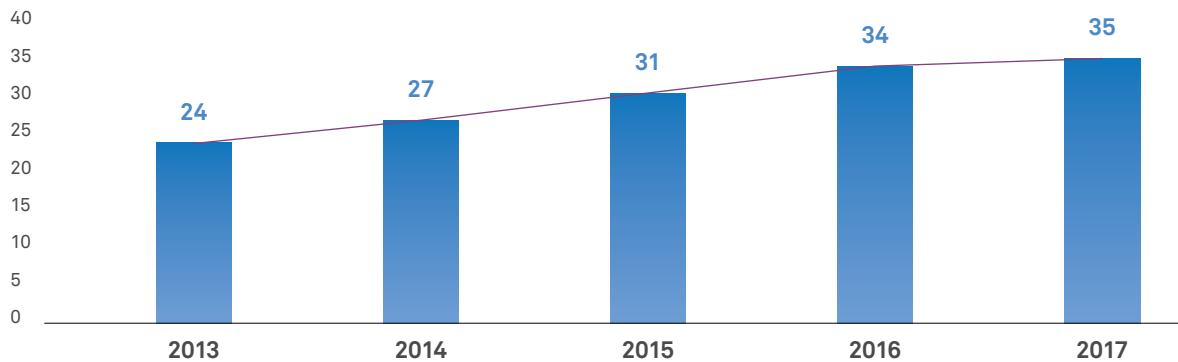


# MEMBERSHIP INSIGHT

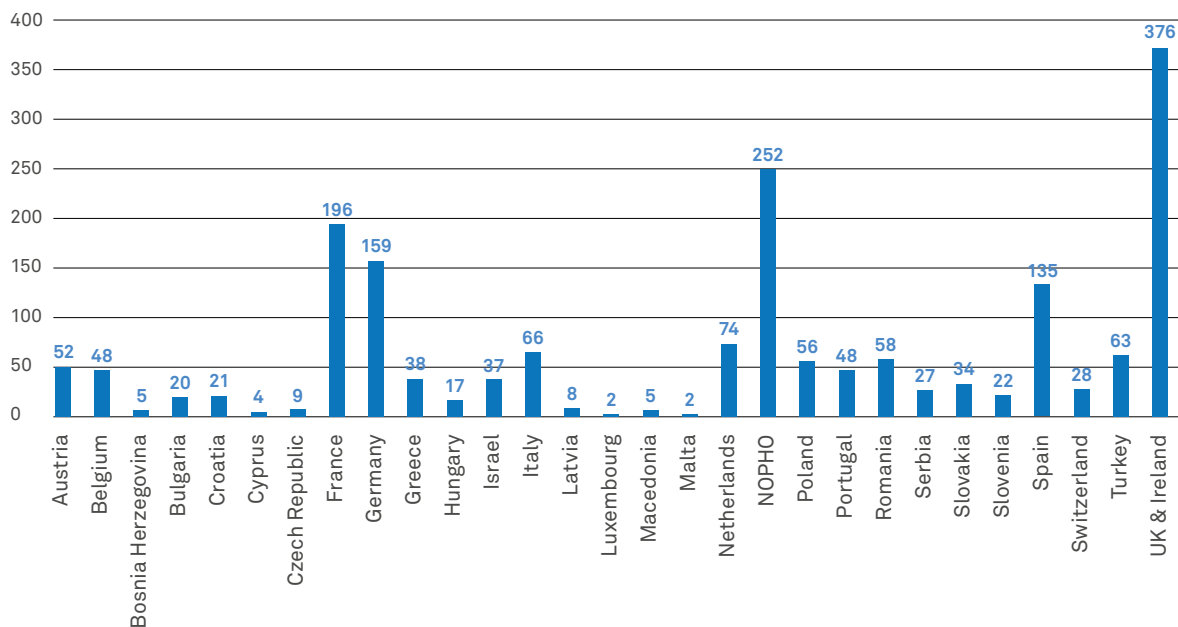
## Membership Over the Years



## Members come from 35 countries representing 30 NaPHOS (National Societies of Paediatric Oncology)

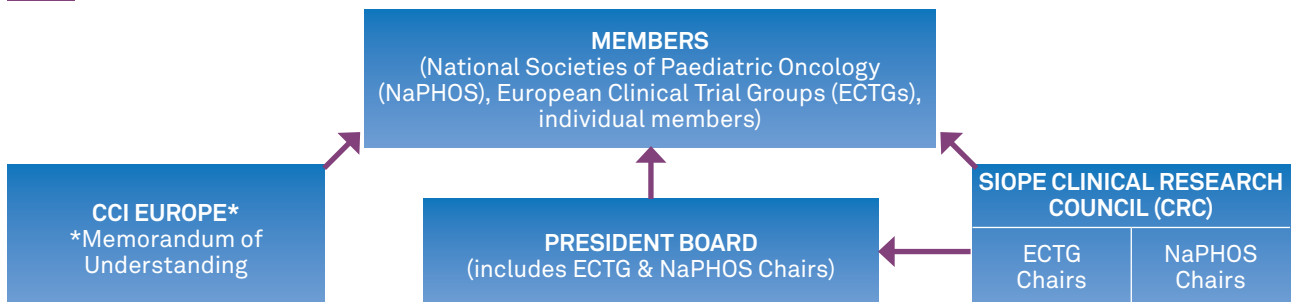


## Members per country (2018)



# GOVERNANCE & FINANCIALS

## > Governance Overview



## > SIOPE Europe Presidents

- Andrea Biondi (2006-2007)
- Kathy Pritchard Jones (2008-2009)
- Ruth Ladenstein (2010-2012)
- Gilles Vassal (2013-2015)
- Martin Schrappe (2016-2018)
- Pam Kearns (2019-2021)

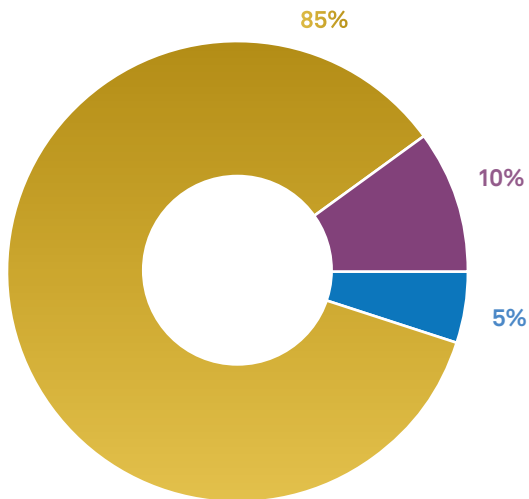


## > SIOPE Europe Board Members

- **President: Pamela Kearns (UK)**, University of Birmingham, Cancer Research Clinical Trials Unit, United Kingdom
- Past-President: Martin Schrappe (DE), University Hospital Kiel, Germany
- Treasurer: Stefan Bielack (DE), Olgahospital, Klinikum Stuttgart, Germany
- Andishe Attarbaschi (AT), St. Anna Children's Hospital, Vienna, Austria
- Carmelo Rizzari (IT), University of Milano-Bicocca, Italy
- Gilles Vassal (FR), Institut Gustave Roussy, Villejuif, France
- François Doz (FR), Institut Curie, Paris, France
- Lars Hjorth (SE), University Hospital Lund, Sweden
- Reineke Schoot (NL), Prinses Máxima Center for Pediatric Oncology, Utrecht, Netherlands
- Ruth Ladenstein (AT), St. Anna's Children's Hospital, Vienna, Austria
- Tom Boterberg (BE), University of Ghent, Ghent, Belgium
- Tomasz Szczepański (PL), Dept. of Pediatric Hematology & Oncology in Zabrze, Poland

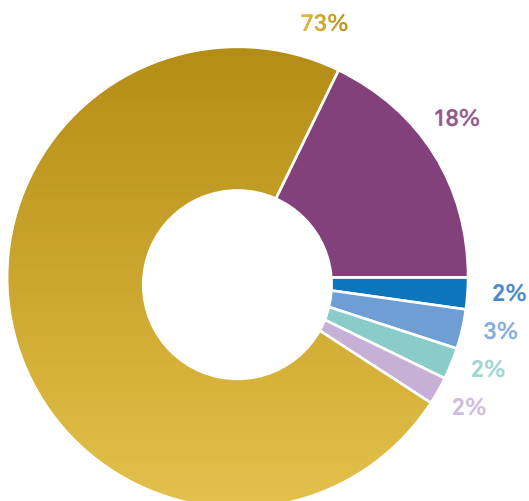
## > Financial Overview

### Revenues 2018



■ EU Projects and Foundations	85%
■ Membership	10%
■ Donations	5%







### Expenditures 2018



■ Staff Costs	73%
■ Overheads & Administration	18%
■ Public Affairs	2%
■ Board & Committees	3%
■ Platforms	2%
■ Grants	2%

# MEDIA & SOCIAL MEDIA COVERAGE

## > Digital and social media impact:

Platforms	2018	% change (from 2017)
 Website unique visitors (12 months in 2018)	22K	+30.8%
 Website number of sessions	31K	+35.8%
 Twitter followers	2.997	+25%
 Number of Tweet impressions	645700	+27%
 LinkedIn connections	557	+39%
 Facebook page followers	381	+100%

## > The media outlets / publications that covered SIOP Europe in 2018:

CancerWorld Magazine 	Open Access Government 
European Journal of Cancer (Elsevier) 	Politico Europe 
European Oncology and Haematology (Touch Oncology) 	SciTech Europa 
Government Gazette 	The European Parliament 



# HEALTH & WELL-BEING ACTIVITY



## Run for Kids with Cancer... Fintro Dwars door Mechelen 30 September 2018, Mechelen, Belgium

On a bright Sunday in Mechelen, around 200 runners joined the Fintro Mechelen Run to raise awareness about health for children and young people. Participants took part in a 5k or 10k run and children aged 4 to 12 years were given the opportunity to complete the 1k run.

This public awareness campaign emphasised SIOPE Europe's role in striving for progress against childhood cancer. SIOPE Europe also employed social media campaign before and during the event to increase the awareness and support for childhood cancer.

This event was a great opportunity to raise awareness about childhood cancer amongst the enthusiastic crowd. Within the lively atmosphere, all the participants made it to the finish line wearing the SIOPE Europe sponsored t-shirts with the message:

**We will not stop when we are tired! We will stop when we are done!**

SIOPE Europe is delighted that so many runners joined this event and thank all the participants and sponsors for their support.



## PARTNERSHIPS

To ensure the best possible care and outcome for all children and young people with cancer in Europe, SIOP Europe has close collaborations with several European organisations representing the point of view of paediatric cancer patients and parents, survivors, paediatricians, adult oncology and rare disease advocates. These include CCI-Europe, SIOP, ITCC, ECCO, ECL, ESMO, ESO, RCE, RareCare, EFGCP and EURORDIS.

Most recently, SIOP Europe also signed a Memorandum of Understanding (MoU) with CCI - Europe and PanCare.



## GOLD RIBBON SYMBOLISM

The gold ribbon is the universal symbol to create awareness about childhood cancer and mobilise increased attention for minimising deaths and disabilities due to childhood cancer. Gold is a precious metal and since children are our most precious treasures, it is indeed a perfect symbol for the childhood cancer journey.



The gold ribbon is used by advocates throughout the world to raise awareness about childhood cancer as well as to encourage people and organisations especially during the Childhood Cancer Awareness Month of September to maximise their support in the fight against childhood cancer.

SIOP Europe has therefore optimised the official logo by integrating the gold ribbon. Going forward, the gold ribbon will be used on various communication material bringing further visibility to the advocacy efforts on childhood cancer.

## KEY DATES

The following are key dates that SIOP Europe observes every year to raise awareness about childhood cancer:

-  **4 February:** World Cancer Day
-  **15 February:** International Childhood Cancer Awareness Day (ICCD)
-  **28 February:** Rare Disease Day
-  **25-31 May:** European Week Against Cancer
-  **September:** Childhood Cancer Awareness Month

Social Media is one of the most common ways to amplify engagement on any topic or issue. Having a greater presence on social media platforms brings more contacts and increased opportunities for visibility. Particularly when social media campaigns are paired with cause awareness days (i.e. #WorldCancerDay), they have the potential to increase effectiveness especially by reaching out to new audiences during these key dates.





SIOPE Europe  
the European Society for Paediatric Oncology

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**20 YEARS OF PROGRESS**  
IN PAEDIATRIC HAEMATO-ONCOLOGY IN EUROPE