

## SIOPE Europe at 20 Years

The European Society for Paediatric Oncology (SIOPE Europe or SIOPE) has reached an important milestone this year celebrating 20 years of activity and progress in paediatric haemato-oncology in Europe. On the occasion of SIOPE Europe's 20<sup>th</sup> Anniversary, and during the Childhood Cancer Awareness Month of September, two events took place in Brussels on Tuesday 25<sup>th</sup> September 2018:

- **[SIOPE –MEPs Against Cancer \(MAC\) Group Policy Event](#)**: Celebrating 20 years of progress in paediatric haemato-oncology in Europe.
- **[SIOPE Europe Gold Ribbon Awards](#)**: Key influencers of the paediatric cancer community were recognised by SIOPE for their outstanding achievements through the Awards Ceremony.

### SIOPE – MAC (MEPs Against Cancer) Event: Celebrating 20 years of progress in paediatric haemato-oncology in Europe



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), the event was an occasion to thank policy-makers for their commitment to the childhood cancer cause and trace the road towards further progress.

Despite being rare, childhood cancer is still Europe's leading cause of children's death by disease over 1 year of age. At the same time, numerous survivors face adverse late-effects that hinder their quality of life and participation in society.

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 said: ***“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.”***



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.

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) said: ***“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 said: ***“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”.***

The need for further multi-stakeholder cooperation was a key theme throughout, including with reference to the prospect of the UK leaving the EU.

Pamela Kearns, SIOPE President-Elect, said: ***“Keywords that have been crucial over the past 20 years at SIOPE 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.

## SIOPE Europe Gold Ribbon Awards 2018



Attended by approximately 100 people from diverse fields, the first edition of the **SIOPE Europe Gold Ribbon Awards** has proven to be an outstanding success.

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.

This exceptional event was also an occasion to mark **SIOPE Europe’s 20<sup>th</sup> Anniversary** thereby 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.



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

**Policy-Makers Awards:**

**Vytienis 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)



**SIOPE Europe Presidents Awards:**

**Andrea Biondi** (SIOPE Europe President, 2005-2007)

**Kathy Pritchard-Jones** (SIOPE Europe President, 2007-2009)

**Ruth Ladenstein** (SIOPE Europe President, 2009-2012)

**Gilles Vassal** (SIOPE Europe President, 2013-2015)

**Martin Schrappe** (SIOPE Europe President, 2016-2018)



**Gold Ribbon:**



The **gold ribbon is the universal symbol to create awareness about childhood cancer** and mobilise increased attention about this disease. 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 work and achievements of the awardees are of vital importance to improving lives and finding cures for children and young people with cancer.

**Event photos:**

[SIOPE – MAC \(MEPs Against Cancer\) Event](#)

[SIOPE Europe Gold Ribbon Awards](#)

## Full details of recipients of the SIOPE Europe Gold Ribbon Awards 2018:

### Vytenis Andriukaitis (European Commissioner for Health and Food Safety)



Vytenis Povilas Andriukaitis was appointed European Commissioner for Health and Food Safety in November 2014.

He was born on 9 August in Siberia where his family was deported in 1941. He returned in 1959 together with his mother and two brothers. His father was allowed to return a year later.

Vytenis Andriukaitis graduated in medicine in 1975 and has been a practicing surgeon, specialising in cardiovascular surgery in

1989, for more than 20 years. He also holds a degree in History from Vilnius University acquired in 1984.

As of 1969, he was active in the anti-Soviet movement. His political engagement started already in 1976. He was one of the founders of the Lithuanian social-democrat party. In 1990, he was elected to the supreme the Supreme Council of the Republic of Lithuania, which preceded Seimas (Lithuanian Parliament) and was one of the co-authors of Constitution of the Republic of Lithuania adopted in 1992 as well as a signatory of independence act of Lithuania.

Andriukaitis was a Member of Parliament for six mandates. During that period, he has been the Deputy Chairman of Committee on European Affairs, the member of Foreign Affairs Committee and Vice-President of Social-Democrat party. The Commissioner has also led the Lithuanian delegation to the Convention on the Future of Europe. From 2012 to 2014, Vytenis Andriukaitis was minister for Health.

### Elena Gentile (Member of the European Parliament, S&D, IT)



Elena Gentile was born in Cerignola (Province of Foggia, Italy), where she currently lives. She successfully graduated in Medicine at the University of Padova in 1978 and worked as a Paediatrician at the Hospital of Cerignola from 1981 to 2005.

Elena Gentile dedicated over 30 years working in regional and local politics. In 1985, she was elected to the Municipal Council of Cerignola and from August 1985 to July 1986 she was Vice-Mayor of Cerignola, responsible for health, environment and social services. From

September 1990 to June 1991 she was Councillor for urban planning and budget administration. In July 1991, she became the Mayor of Cerignola. From May 2005 to June 2014, she was member of the Regional Assembly in Puglia holding high-profile ministers in the regional government, being responsible for Welfare and Social Affairs and then for Health. From December 2013, she was Member of the National Board of the Democratic Party in Italy. In 2014, Elena Gentile was elected to the European Parliament representing the electoral district of Southern Italy and joined the group of the Progressive Alliance of Socialists and Democrats (S&D). Elena Gentile is currently Full Member of the Committee on Employment and Social Affairs and of the Delegation to the EU-Montenegro Stabilisation and Association Parliamentary Committee. She is also substitute member in the Committee on Regional Development, in the Committee on Environment, Public Health and Food Safety and in the Committee of Culture and Education as well as in the Delegation for relations with Bosnia Herzegovina and Kosovo.

### Françoise Grossetête (Member of the European Parliament, EPP, FR)



A law graduate, Françoise Grossetête started her career in France as a local politician in her hometown of Saint-Etienne before being elected as Member of the European Parliament for the first time in 1994. Since then, she has been constantly re-elected, the last time in 2014. A member of Les Républicains (LR) and the European People Party (EPP), she is sitting in the committee for the environment, public health and food safety, and the committee for energy, industry and research. She is also Vice-President of the EPP Group in Parliament since 2014. During her mandates, Françoise

Grossetête specialised in health policy and has been working closely on the pharmaceutical regulation as a Parliament rapporteur, amongst other texts including the Regulation for orphan medicinal products and the Directive for cross-border healthcare.

## Alojz Peterle (Member of the European Parliament, EPP, SL and President of the MEPs Against Cancer Group – MAC)



Alojz Peterle is a Member of the European Parliament for the EPP since 2004, the same year Slovenia became an EU Member State. In 1990, Alojz Peterle became the first democratically elected Prime Minister of Slovenia and later also held the position of Minister of Foreign Affairs. He has been a Member of the Foreign Affairs Committee and a substitute Member of the Committee on Environment, Public Health and Food Safety and from February 2018 also Member of the Pesticides Committee.

Following his own personal experience with cancer, Alojz Peterle has devoted considerable efforts to raising the political awareness of fighting and preventing cancer all across Europe by founding the informal all-party forum ‘Members Against Cancer’ and has been particularly committed to promoting complementary and alternative medicine (CAM). Alojz Peterle dedicated a big share of the past ten years of his professional endeavours to make it obvious to the broader public that health is not only a matter for individual citizens, but also a concern we share as Europeans.

## Dame Glenis Willmott (former Member of the European Parliament, S&D, UK)



Dame Glenis Willmott (S&D, UK) is a former MEP who most recently was a full member of the Environment, Public Health and Food Safety Committee (ENVI) of the European Parliament and Co-Chair of its Health Working Group.

Glenis Willmott was born in County Durham in North East England, was educated in Mansfield and at Trent Polytechnic where she obtained an HNC in medical science. She was rapporteur on the Medical Devices Regulation 2012/0266 (COD) and was previously Rapporteur on the Clinical Trials Regulation (EU) No 536/2014. Fighting childhood cancer has been one of the key long-standing aims of MEP Willmott. Thus, as Rapporteur on the Clinical Trials Regulation, MEP Willmott set out to introduce important changes to rules governing cross-border clinical trials – essential for life-saving progress in child cancers as rare diseases. Over almost 2-years, she engaged in inter-institutional negotiations, fostering a landmark agreement that are uniquely positioned to address existing challenges. Moving towards the implementation of the newly adopted Clinical Trials Regulation in the coming years, MEP Willmott remained actively involved with regards to transparency provisions and national insurance schemes to further boost clinical trial activity.



Glenis Willmott was also active on the Paediatric Medicine Regulation (1901/2006/EC and 1902/2006/EC), where she called on the European Commission to rectify the guidelines on exemptions and, most recently, to consider an earlier revision of the legislation to ensure that opportunities are maximised for children with cancer. She was also the host of five consecutive editions of the International Childhood Cancer Day at the European Parliament in cooperation with SIOPEurope. SIOPEurope and the pan-European paediatric haematology oncology community applaud the hard work and dedication of Glenis Willmott to facilitating life-saving health care, research and innovation.

### Childhood Cancer International (CCI-Europe)



Childhood Cancer International (CCI; formerly International Confederation of Childhood Cancer Parent Organizations) was founded in 1994 as an umbrella organisation of childhood cancer grassroots and national parent organisations. Today, CCI is the largest patient support organisation for childhood cancer. It is a global, parent-driven non-profit that represents 188 parent organisations, childhood cancer survivor associations, childhood cancer support groups, and cancer societies, in 96 countries, across 5 continents.

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

CCI-Europe is the continental branch of the global organisation CCI. As the voice of the children/adolescents, the survivors and their families, who have endured the childhood cancer journey, CCI-Europe advocates for the rights of children/adolescents with cancer and prioritises 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.

### Andrea Biondi (SIOPE Europe President, 2005-2007)

Andrea Biondi is Full Professor of Paediatrics at the Faculty of Medicine and Surgery, and Director of the Department and the School of Paediatrics, University of Milano-Bicocca, San Gerardo Hospital, Monza (MI), Italy.



Andrea Biondi was born in Pontremoli (MS), Italy. In 1979, he received his medical degree from the University of Milan and achieved further specialisation in Paediatrics from University of Milan (1982) and in Haematology from University of Bari (1994). He is head of the 'M.Tettamanti Research Centre' and 'Stefano Verri Cellular and Gene Therapy Laboratory' San Gerardo Hospital, Monza (MI), Italy. He is also Scientific Director of the Fondazione 'M. Tettamanti – M. De Marchi' Onlus since 2006. He started chairing the PhD Program in Molecular and Translation Medicine (DIMET) of the University of Milano-Bicocca in 2007 and became Pro-Rector for International Affairs of the University of Milano-Bicocca in August 2013. His scientific research activity, mainly focused in the field of molecular genetics of childhood leukaemia and immuno and cell therapy of leukaemia, has resulted in several hundreds of publications on international peer reviewed journals. He is member of

many scientific societies and is actively involved in the site visit and funding programs of these international organisations/agencies. From 2012 to 2015, he was President of the Italian Society of Paediatric Haematology and Oncology (AIEOP) and became Chairman of the International BFM Study Group (I-BFM-SG) in April 2016. Besides holding positions at various European and international medical societies, Andrea Biondi was the first President of SIOPE Europe (2005-2007).

### Kathy Pritchard-Jones (SIOPE Europe President, 2007-2009)

Professor of Paediatric Oncology, University College London, United Kingdom.



Kathy Pritchard-Jones is Professor of Paediatric Oncology at UCL Institute of Child Health and a consultant oncologist at Great Ormond Street Hospital. She is one of the UK's foremost experts in childhood cancer, where she has extensive experience of partnership working to deliver complex care and enable research, running international clinical trials and a translational research laboratory focussed on kidney cancers of childhood. She was also Chair of the SIOPE Europe Clinical Trials committee (2004-2007) and then President of SIOPE Europe (2007-2009). She has published over 200 articles in the field of childhood cancer, including collaborative research with a medical sociologist on information needs and issues surrounding consent for clinical trials and banking of tissues for research from children and adolescents with cancer and their families.

Kathy Pritchard-Jones is also chief medical officer for an integrated cancer system, London Cancer, where since 2010, she has led redesign of whole pathways of cancer care for a population of 3.2 million in North and East London in partnership with patients, primary care, public health and the voluntary sector aiming to improve clinical outcomes, patient experience of care and access to clinical trials and innovation.

### Ruth Ladenstein (SIOPE Europe President, 2009-2012)

Professor in Paediatrics and Senior Consultant in Paediatric Oncology of the St. Anna Children's Hospital, Head of the Clinical Trials Unit S2IRP at the Children's Cancer Research Institute (CCRI), Vienna, Austria.



Ruth Ladenstein was born in Vienna, Austria, received her Doctorate of Medicine in 1982 and is permanently affiliated with St. Anna Children's Hospital in Vienna. Ruth Ladenstein is also Project Coordination for the European Reference Network in Paediatric Cancer (ERN PaedCan) since 2017, the European Expert Paediatric Oncology Research Network for Diagnostics and Treatment (ExPO-r-NeT) 2014 – 2017, the European Network for Cancer Research in Children and Adolescence (ENCCA) 2011 – 2015 and the Austrian Medicine for Children Research Network OKIDS GmbH since 2012. Ruth Ladenstein was President of SIOPE Europe during 2009-2012.

Other roles include Advisory Board Member of the SIOPE Europe Neuroblastoma Group since May 2011; former SIOPEN president from 2007-2011; Principle Coordinating Investigator of SIOPEN High Risk Neuroblastoma Trials since 2002. She is also Chair of the Austrian Group for Paediatric Haematology-Oncology and Member of Oncology Advisory Board of the Ministry of Health Austria since 2013.

## Gilles Vassal (SIOPEurope President, 2013-2015)

Professor Oncology & Head of Clinical Research Division, Institut Gustave Roussy, Paris, France.



Trained as a Paediatric Oncologist, Gilles Vassal received his PhD in Pharmacology. He is Professor of Oncology in University Paris XI and is currently head of Clinical Research at Institut Gustave Roussy, a large cancer centre with 11000 new patients annually. For the last 20 years, Gilles Vassal has dedicated his research, clinical and training activity to the development of new drugs for children and adolescents with cancer. He co-founded three European networks: the EU academic Consortium for Innovative Therapies for Children with Cancer (ITCC), the European Network for Cancer research in Children and Adolescents (ENCCA) and the European Expert Paediatric Oncology Reference Network for Diagnostics and treatment (ExPO-r-Net). He coordinated two European projects (KidsCancerKinome and O3K).

He is currently chair of ITCC chair, a network that conducts a comprehensive new drug development program from the biology and preclinical evaluation to the early drug trials in 7 EU member states. He was President of SIOPEurope (2013-2015) driving the EU Paediatric Oncology Policy agenda of several topics such as the CT regulations, Data Protection & Paediatric Regulation. He is Board & Founding Member of the European CanCer Organisation (ECCO). Author of more than 170 publications and expert at the European Medicine Agency and member of several Scientific Councils.

## Martin Schrappe (SIOPEurope President, 2016-2018)

Full Professor of Paediatrics and Director of the Department of General Paediatrics at the University Medical Centre Schleswig-Holstein, Christian-Albrechts University of Kiel (Germany).



Member of the SIOPEurope Board since 2009, Martin Schrappe is Full Professor of Paediatrics and Director of the Department of General Paediatrics at the University Medical Centre Schleswig-Holstein, Christian-Albrechts University of Kiel (Germany). Martin Schrappe has an extensive knowledge on the clinical and biological aspects of paediatric oncology, with an emphasis on leukaemia therapy, as well as a long and international reputation as Chairman of the International BFM Study Group. Board Member of various national and international clinical study groups for paediatric haematology and oncology, Martin Schrappe is one of the Activity Coordinators of the ENCCA project, current SIOPEurope President (2016-2018) and represents SIOPEurope within the Board of the European CanCer Organisation (ECCO).



### About SIOPE Europe:



The European Society for Paediatric Oncology (SIOPE Europe or SIOPE) is the only pan-European organisation representing all professionals working in the field of childhood cancers. With more than 1,735 members across 35 countries, SIOPE is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe. The SIOPE Strategic Plan 'A European Cancer Plan for Children and Adolescents' includes specific objectives and implementation platforms to achieve this mission. Learn more: [www.siope.eu](http://www.siope.eu) and follow us on [Twitter](#), [LinkedIn](#) & [Facebook](#).

### About MAC (MEPs Against Cancer):



The MAC Group was founded in 2005 and remains the only dedicated group to cancer policy at the European Parliament. There are currently 38 MAC members coming from all political groups and different EU Member States. The President Mr. Alojz Peterle (EPP, Slovenia), Vice-Presidents Ms. Nessa Childers (S&D, Ireland), Mr. Pavel Poc (S&D, Czech Republic), and Dr. Charles Tannock (ECR, United Kingdom), and other members are committed to taking action in the fight against cancer. The MEPs Against Cancer work together in order to improve cancer control in Europe, in the belief that European cooperation adds value to member state actions. In order to address the challenges faced by the EU, MAC MEPs collaborate with the European Commission, the Council and other relevant organisations to reduce cancer incidence by 15% by 2020. [www.mepsagaincancer.eu](http://www.mepsagaincancer.eu); Twitter: [@MAC\\_MEPs](#).

### About ECL:



The Association of European Cancer Leagues (ECL) is a non-profit, pan-European umbrella organisation of national and regional cancer societies. Located in Brussels, ECL provides an exclusive platform for members to collaborate with their international peers, primarily in the areas of cancer prevention, tobacco control, access to medicines and patient support, and creates opportunities to advocate for these issues at the EU level.

ECL's VISION: Europe free of cancers

ECL's MISSION: To advocate for improved cancer control and care in Europe through facilitating collaboration between cancer leagues, and influencing EU and pan-European policies.

For more information, visit [www.europeancancerleagues.org](http://www.europeancancerleagues.org) and follow [@cancerleagues](#) on [Twitter](#) and [Facebook](#).

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SIOPE Europe  
the European Society for Paediatric Oncology

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