PanCareSurFup for Childhood Cancer Survivors European Conference

23-24 May 2016  ▪  Brussels, Belgium

ACTING NOW!

IN ASSOCIATION WITH EUROPEAN WEEK AGAINST CANCER (25-31 May each year)
PROGRAMME OVERVIEW

The 2-day PanCareSurFup for Childhood Cancer Survivors European Conference ‘Acting Now!’ will address current challenges in ensuring the quality of survivorship. As one of the main objectives of the broader SIOPE Strategic Plan – A European Cancer Plan for Children and Adolescents, the research performed by PanCareSurFup partners is essential to educate both former patients and healthcare professionals. The Conference also aims to empower survivors to play an active role in maintaining their own health and well-being with specific tools, like the ‘Survivorship Passport’.

PanCareSurFup - PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies (www.pancaresurfup.eu) is a consortium of 16 European institutions in 11 countries, funded by the 7th Framework Programme of the European Commission, to carry out research studies into the late effects of cancer treatments, to establish guidelines for follow-up, to disseminate the results and to provide training and workshops for stakeholders. The goal is to provide every European childhood cancer survivor with better access to care and better long-term health. The project commenced in February 2011 and will run until January 2017.

CONFERENCE VENUE AND ACCOMMODATION

Thon Hotel EU
Rue de la Loi 75, B-1040 Brussels
Phone: +32 (0)2 204 3911

PARLAMENTARIUM MUSEUM

A tour of the Parliamentarium Museum will take place on Monday, May 23rd at 6.15pm. This venue is just a 5-10 minute walk from the Thon Hotel EU and the tour will take approximately one hour. The Parliamentarium will make you experience the European Parliament as never before, making you discover in a refreshingly new way more about the institution that represents you. Dynamic, interactive multimedia displays will guide visitors through the journey of European integration and the impact this has on our everyday lives. Find out more on www.europarl.europa.eu/visiting/en/visits/parlamentarium.html

NETWORKING DINNER

A networking dinner will take place on Monday, May 23rd at 7.30pm in the Thon Hotel EU. We would be delighted if you can join us: this is your opportunity to meet and network with your colleagues and with the experts.
If you wish to attend this event, please indicate this on your registration form. Places are limited and subject to availability.
PanCareSurFup Participants & Conference Organizing Committee

**Lars Hjorth**  
Project Co-ordinator  
Lund University  
Lund, Sweden

**Momcilo Jankovic**  
Work Package Leader  
Fondazione MBBM  
Monza, Italy

**Stanislaw Garwicz**  
Work Package Leader  
Lund University  
Lund, Sweden

**Riccardo Haupt**  
Project Partner  
Istituto Giannina Gaslini  
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**Roderick Skinner**  
Work Package Leader  
Great North Children’s Hospital, Royal Victoria Infirmary, Newcastle upon Tyne, UK

**Carlotta Sacerdote**  
Project Partner  
Centro di Riferimento per l’Epidemiologia e la Prevenzione Oncologica, Turin, Italy

**Edit Bárdi**  
Project Partner  
USEM, Semmelweis University  
Budapest, Hungary

**Gillian Levitt**  
Project Partner  
Great Ormond Street Hospital for Children  
NHS Trust, London, UK

**Julianne Byrne**  
Project Partner  
Boyne Research Institute, Drogheda, Ireland

**Claudia Kuehni**  
Project Partner  
Institute of Social and Preventative Medicine, University of Bern, Bern, Switzerland

**Mike Hawkins**  
Work Package Leader  
Centre for Childhood Cancer Survivor Studies  
University of Birmingham, Birmingham, UK

**Leontien CM Kremer**  
Work Package Leader  
Academic Medical Centre, Emma Children’s Hospital, Amsterdam, The Netherlands

**Florent de Vathaire**  
Work Package Leader  
Institut Gustave Roussy, Villejuif, France

**Eva Frey**  
Project Partner  
St. Anna Children’s Hospital, Vienna, Austria

**Heleen van der Pal**  
Organizing Committee  
Academic Medical Centre, Amsterdam, The Netherlands

**Peter Kaatsch**  
Joint Work Package Leader  
UMC-Mainz, IMBEI  
Mainz, Germany
Desiree Grabow  
Joint Work Package Leader  
UMC-Mainz, IMBEI  
Mainz, Germany

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Project Partner  
IARC  
Lyon, France

Samira Essiaf  
Project Partner  
SIOPE  
Brussels, Belgium

Giulia Petrarulo  
Organizing Committee  
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Helena Linge  
Project Manager  
Lund University  
Lund, Sweden

Elise Witthoff  
Project Manager  
Lund University  
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Niamh Corbett  
Organizing Committee  
Boyne Research Institute  
Drogheda, Ireland

Rosaire Kelly  
Organizing Committee  
Boyne Research Institute  
Drogheda, Ireland

Meriel Jenney  
Department of Child Health,  
Cardiff and Vale NHS Trust, UK

Peter Inskip  
Radiation Epidemiology Branch, National  
Cancer Institute, NIH, Bethesda, MD, USA

Jörn Beck  
Klinik für Kinder und Jugendliche,  
Friedrich Alexander Universität  
Erlangen-Nürnberg, Germany

Gerlind Bode  
Former CEO of the German umbrella  
organisation of all parent initiatives (Germany  
Childhood Cancer Foundation), Germany
DAY 1  Monday 23 May 2016

12:00 - 13:00  Lunch

SESSION 1 : WELCOME, INTRODUCTION & SETTING THE STAGE
Moderator: Vivienne Parry (Science writer and broadcaster, UK)

13:00  Opening address
Alojz Peterle, MEP (EPP, SL) and President of the MEPs Against Cancer (MAC) Group

13:15  Introduction to PanCareSurFup
Lars Hjorth (PanCareSurFup, Lund University, SE)

13:30  Survivors’ experiences: What are the needs of survivors/families at different time points after diagnosis?
Victoria Forster (Northern Institute for Cancer Research, UK)
Tom Grew (UK)
Holly Wattwil (Childhood Cancer International, SE)

14:20-14:40  Coffee break

SESSION 2 : THE PANCARESURFUP CONSORTIUM
Moderator: Vivienne Parry (Science writer and broadcaster, UK)

14:40  Keynote lecture:
Success story: Increased survival after childhood cancer – a coin with two sides
Stanislaw Garwicz (PanCareSurFup, Lund University, SE)

15:10  Highlights and progress of PanCareSurFup
Lars Hjorth (PanCareSurFup, Lund University, SE)

15:20  Where did the data for PanCareSurFup come from?
Desiree Grabow (PanCareSurFup, German Childhood Cancer Registry, DE)

15:30  The role of dosimetry in risk assessment
Florent de Vathaire (PanCareSurFup, Institut Gustave Roussy, FR)

15:40  Damage to the heart from cancer treatment
Leontien Kremer (PanCareSurFup, Emma Children’s Hospital, AMC, Cochrane Childhood Cancer Group, NL)

15:50  Causes and prevention of further cancers
Mike Hawkins (PanCareSurFup, University of Birmingham, UK)

16:00  Panel Discussion & Audience participation

16:20-16:30  Short break
ACTIVITIES IN AND FOR THE SURVIVOR COMMUNITY

Moderator: Vivienne Parry (Science writer and broadcaster, UK)

16:30 Survivors breaking barriers:

Chairs: Julianne Byrne (PanCareSurFup, Boyne Research Institute, IE)
        Momcilo Jankovic (PanCareSurFup, Foundation MBBM, IT)

Participants: Jaap den Hartogh (VOKK, NL)
              Tom Grew (UK)
              Eleonora Guzzi (IT)
              Katie Rizvi (Little People, RO)
              Daniel Tomai (RO)
              Holly Wattwil (Childhood Cancer International, SE)

• Testimonials from survivors
• Video(s)
• Irish survivor meeting
• Race of brave bikers (Marostica)
• Kilimanjaro climb
• Survivor meetings in The Netherlands

17:30 Panel Discussion on activities in and for the survivor community

Audience participation

18:15 Visit to the Parlamentarium Museum

5-10 minutes’ walk from Thon Hotel EU

19:30 Social dinner, Thon Hotel EU

Surprise entertainment after dinner

DAY 2   Tuesday 24 May 2016

08:00 - 09:00 Breakfast

SESSION 3: THE IMPACT OF LATE EFFECTS

Moderator: Vivienne Parry (Science writer and broadcaster, UK)

09:00 Introduction

Lars Hjorth (PanCareSurFup, Lund University, SE)

09:05 Survivor’s story

Sarah Quigley (IE)

09:20 Creating guidelines for long term follow-up

Rod Skinner (PanCareSurFup, Great North Children’s Hospital, UK)

09:45 The Survivorship Passport: achievements and future developments

Riccardo Haupt (PanCareSurFup, Institute G. Gaslini, IT)

10:05 Delivering long-term care

Heleen van der Pal (PanCareSurFup, Outpatient Clinic for the Late Effects of Treatment for Childhood Cancer, AMC, NL)
10:20 The Clinical Perspective

Panel discussion & Audience participation
Psychologist: Johanna Blom (University of Modena, IT)
General Practitioner: Cathy Burton (Macmillan Cancer Support, UK)
Occupational Physician: Enrico Pira (University of Turin, IT)
Endocrinologist: Natascia Di Iorgi (Istituto G. Gaslini, IT)
Reproductive Specialist: Marianne van de Wetering (Emma Children’s Hospital, AMC, NL)

11:20-11:45 Coffee break

SESSION 4: ROAD TO THE FUTURE

Moderator: Lars Hjorth (PanCareSurFup, Lund University, SE)

11:45 Equal access to care, research projects and training for care and research
Martin Schrappe (SIOPE, University Medical Centre Schleswig-Holstein, DE)

12:00 Other current EU initiatives: ENCCA, PanCareLIFE, ExPO-r-Net and future EU projects
Martin Schrappe (SIOPE, University Medical Centre Schleswig-Holstein, DE)

12:15 How long-term follow up can be integrated into new clinical trials
Ruth Ladenstein (CCRI, St. Anna Children’s Hospital, AT)

12:30 Potential future directions for ‘outcomes’ research relating to survivors
Mike Hawkins (PanCareSurFup, University of Birmingham, UK)

12:45 What would clinicians (doctors/nurses) like from future research?
Monica Terenziani (Foundation IRCCS Istituto Nazionale dei Tumori, IT)

13:00-14:00 Lunch

14:00 Message from European Commission Scientific Officer responsible for PanCareSurFup
Dominika Trzaska (DG Research & Innovation, European Commission, BE)

14:10 Ethical aspects associated with survivorship research and care
Meriel Jenney (Children’s Hospital for Wales, UK)

14:30 Implementation of long-term follow-up guidelines & the Survivorship Passport
Rod Skinner (PanCareSurFup, Great North Children’s Hospital, UK)
Riccardo Haupt (PanCareSurFup, Institute G. Gaslini, IT)

15:00 Sustainability of guidelines and international collaborations
Leontien Kremer (PanCareSurFup, Emma Children’s Hospital, AMC, Cochrane Childhood Cancer Group, NL)

15:30 Panel discussion: What would a perfect world for survivors look like?
Audience participation

15:50 Summary & Take Home Messages
Lars Hjorth (PanCareSurFup, Lund University, SE)

16:00 Farewell
CONFERENCE SPEAKERS

Cathy Burton  
Macmillan Cancer Support  
London, United Kingdom

Julianne Byrne  
Chief Executive Officer  
Boyne Research Institute  
Drogheda, Ireland

Florent de Vathaire  
Director Epidemiology of Radiation  
Institut de cancérologie Gustave-Roussy Villejuif, France

Jaap den Hartogh  
Policy Officer for survivors at VOKK, VOX’s Founder  
Vereniging Ouders, Kinderen en Kanker Nieuwegein, The Netherlands

Natascia Di Iorgi  
Endocrinologist  
Istituto Giannina Gaslini  
Genova, Italy

Victoria Forster  
Research Associate  
Northern Institute for Cancer Research  
Newcastle, United Kingdom

Stanislaw Garwicz  
Paediatric Oncology Professor  
Dept. Clinical Sciences, Lund University  
Lund, Sweden

Desiree Grabow  
Epidemiologist  
German Childhood Cancer Registry at IMBEI, UMC-Mainz  
Mainz, Germany

Tom Grew  
Childhood cancer survivor  
United Kingdom

Eleonora Guzzi  
Childhood cancer survivor  
Future Leaders Program, GlaxoSmithKline  
Verona, Italy

Riccardo Haupt  
Dept. of Epidemiology and Biostatistics  
Istituto Giannina Gaslini  
Genova, Italy

Mike Hawkins  
Epidemiology Chair & Centre Director  
University of Birmingham  
Birmingham, United Kingdom

Lars Hjorth  
Consultant Paediatric Oncology  
Skåne University Hospital, Dept. of Clinical Sciences, Lund University  
Lund, Sweden

Momcilo Jankovic  
Responsible Haemato-Oncology  
Paediatric Outpatient Clinic  
Fondazione MBBM  
Monza, Italy

Meriel Jenney  
Paediatric Oncology Dept.  
Children’s Hospital for Wales  
Cardiff, United Kingdom

Leontien Kremer  
Paediatrician  
Emma Children’s Hospital, Cochrane  
Childhood Cancer Group  
Amsterdam, The Netherlands
Ruth Ladenstein
Head of the Clinical Trials Unit S²IRP, ExPO-r-Net Coordinator & SIOPE Board member, St. Anna’s Children’s Hospital Vienna, Austria

Johanna MC Blom
Consultant in Paediatric and Clinical Neuroscience and Developmental University of Modena Modena, Italy

Vivienne Parry
Science writer and broadcaster London, United Kingdom

Alojz Peterle
MEP (EPP, Slovenia) & President of the MEP Against Cancer (MAC) Group European Parliament Brussels, Belgium

Enrico Pira
Dept. of Public Health and Paediatrics Università degli Studi di Torino Turin, Italy

Sarah Quigley
Childhood cancer survivor Dublin, Ireland

Katie Rizvi
Founder and CEO Association ‘Little People’ Cluj-Napoca, Romania

Martin Schrappe
SIOPE President, Director Dept. of General Paediatrics, University Medical Centre Schleswig-Holstein Kiel, Germany

Rod Skinner
Consultant in Paediatric and Adolescent Oncology / BMT Great North Children’s Hospital, Newcastle, United Kingdom

Monica Terenziani
Paediatric Oncology Unit Found. IRCCS Istituto Nazionale dei Tumori Milan, Italy

Daniel Tomai
Childhood cancer survivor Romania

Dominika Trzaska
Scientific Officer Directorate-General for Research and Innovation, European Commission Brussels, Belgium

Marianne van de Wetering
Paediatric Oncologist Emma Children’s Hospital Amsterdam, The Netherlands

Heleen van der Pal
Outpatient Clinic for the Late Effects of Treatment for Childhood Cancer Academisch Medisch Centrum Amsterdam, The Netherlands

Holly Wattwil
Barncancerfonden Södra Board Member Childhood Cancer International Lund, Sweden
MY TAKE-HOME MESSAGE FROM THE CONFERENCE IS:
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Dissemination Partner
www.siope.eu