European Network of Youth Cancer Survivors

EU-CAYAS-NET

Participants

Training event
8-10 February 2023, Brussels

Ana Amariutei

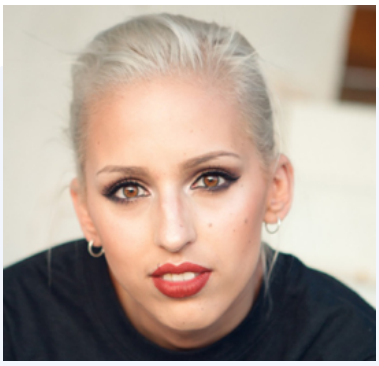
Cancer survivor, patient advocate at Youth Cancer Europe and Biomedical Science PhD student at University of Sheffield.

TW: AEcaterina
IG: ecaterinaana

Ana Totovina

My name is Ana. I'm a cancer survivor from Romania. I'm working for Youth Cancer Europe and Little People Romania. I had treatment for leukemia 10 years ago. My passion is dancing and playing the piano.

TW: Ana_Totovina
IG: ana.toto08



Andrea Ruano

Ewing Sarcoma survivor, Spaniard, Art director & Graphic designer, based in the UK, member of the Steering Committee of Youth Cancer Europe. Photography and cheese lover, proud owner of a golden leg.

TW: @ruanoide
IG: ruanoide

Andrijana Serafimovska

My name is Andrijana Serafimovska. I am from Skopje, N. Macedonia and I am 25 years old.

IG: andrijanaserafimovska

Ania Buchacz

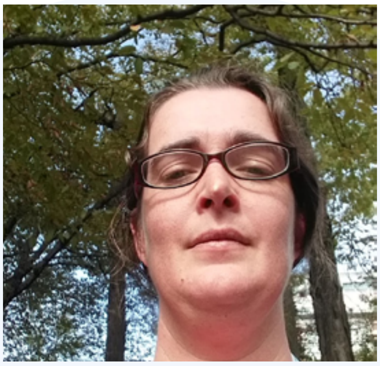
Rhabdomyosarcoma survivor, patient advocate with strong focus on Quality of Life for CAYAS and Cross Border Healthcare. Member of the Steering Committee of the Youth Cancer Europe. Founder of Fundacja Pani Ani. Psycho oncologist. Based in Poland and Austria.

TW: FundacjaPaniAni
IG: ania_b_u

Aoife Moggan

I'm Aoife (EFA) from Ireland and I'm a patient advocate with Childhood Cancer Ireland (CCI). I was diagnosed with a spinal Astrocytoma at 13 and have been dealing with the complicated domino effect of its impact ever since. I have a degree in psychology. I love to be creative, many of my stories begin with "I was listening to this podcast and .." and am happiest surrounded by my family and friends, preferably when there is food involved!

TW: aoifemoggan
IG: aoifemoggan



Ardine Reedijk

My name is Ardine Reedijk, I am 42 years old. At age 11, I was diagnosed with acute lymphoblastic leukemia. I like doing research with (cancer) data instead of seeing sick people, therefore I became an epidemiologist instead of a doctor.In 2021 I successfully defended my thesis entitled "Progress against childhood and young adolescent cancer in the Netherlands since 1990". I live in a small village in the Southwestern part of the Netherlands, together with my husband and 2 children. I enjoy every day and I am very pleased with our house and social network. In my free time I like to bake cakes with the children.

Aušrinė Kėvalaitė

I am a friendly, active person who really loves nature, animals and bees (it is the reason why I am becoming a beekeeper)! I also like to delve into people's thinking and behavior so now I am studying for a master's degree in clinical health psychology.

IG: k._bitute

Asimo Menia Koukougianni

Menia is the co-founder and manager of NGO KARKINAKI, Awareness for Childhood and Adolescent Cancer, an advocacy organization, founded by parents in 2015. As a parent advocate, she is a EUPATI Fellow, board member of the Pan European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare), member of the Childhood Cancer International Europe (CCI Europe), member of the children's medicine working party of the European Forum for Good Clinical Practice (EFGCP) and member of the Data Advisory Group of EURORDIS. She is also member at the Patients Expert Group of the European Organization for Research and Treatment of Cancer (EORTC) and member of the Scientific Advisory Group of Oncology of the European Medicines Agency (EMA) Recently, she became member at the AMR Patients Group of Health First Europe and member of the AMR Stakeholders Network.

TW: MENIAKOUKOUGIA
IG: meniakoukougianni

Bojan Ristovski

If you hear someone talking a lot at this event that would be me. I'm Boki Youth Cancer Activist Event Organizer & Community Manager that helps brands, organizations, and individuals grow their communities on social media by building relationships with their audience. My experience includes ideating, creating, and implementing people-first content marketing strategies and managing social media channels for companies in various industries, startups, and NGOs. In my spare time, you find me volunteering in Youth Cancer & Student organizations, traveling, hiking, partying, riding my bike, and reading a good business or modern psychology book.

IG: bokibf

Carmen Monge

I am a day-dreamer, scientist, and foodie from Costa Rica/NL. I love to learn from people around the world, and have insightful conversations, normally with a good cup of coffee. Since my treatment, I have participated in several events for cancer survivors, where I have developed meaningful relationships that motivate me to keep building better conditions for us.

IG: _carmenmonge

Colette Ryan

I live in a rural area in the sunny South East in Ireland. Having lived in Canada for a couple of years, I moved home following my first diagnosis. I was diagnosed with breast cancer and an incidental finding of thyroid cancer at 31/32. I have been on the board of YouCan Ireland as patient advocate since 2021, and also been involved with YCE since 2019. I now work part time, which allows me time and space to be involved with these organisations. In my free time I like to create, with crochet, growing veggies and cooking.

IG: Ettiecol

Elena Arsenie-Constantinescu

Cancer Patient Advocate. Love to bring an impact in society and in people's life by leading educational projects, teaching, training and motivating. Highly passionate about marketing, design and project management. Entrepreneurship oriented.

TW: Elenaa_AC
IG: elena_ac13

Eline Van der meulen

28, living in Amsterdam (yes, available as tour guide ;)), studied biomedical- and health sciences and now working as project leader and research coordinator. Also: Part of CCI's survivorship pillar, the dutch childhood cancer Organization as well as the Prinses Máxima Centre. I hope that, by working together, every survivor gets the care that's wanted and needed.

IG: Elinevandermeulen

Emilija Gimžauskaitė-Česlevičienė

My name is Emilija, from Lithuania. I'm I am a nature person and I really like to spend my time in forest

Erik Sturesson

I survived cancer at 15 and have struggled with many things since, with mental health and fatigue being a big issue for me since the treatment, but also physical ailments like diabetes and endocrine issues. In May 2022, at roughly 17:00 I quit with morphine after having taken it since my cancer treatment, for more than 12 years. I feel less and less like crap every day.

Hannah Gsell

I am a 31-year-old psychologist and survivor from Austria. I was diagnosed with ALL at the age of 14. Since 2012, I have been active at the national level as a patient representative for Survivors Austria, and since 2019 also at the EU level. Since 2020 I am the chairwoman of the patient organization Survivors Austria. In addition to my work as a psychologist, I have been working at CCI Europe as a project manager in two (further) EU projects and one national project since 2020.

Helen Rolf

I'm Helen and am 48 years old. I am British but have lived by the sea in Gothenburg, Sweden for the last 9 years. I was diagnosed with a Wilms Tumour at the age of 16 months and was treated at Sheffield Children's Hospital with chemo and radiotherapy. I went on to train as a doctor (paediatrician) but unfortunately had to give up work due to the Late Effects of my treatment. I have had experience of Late Effects clinics in both the UK and Sweden. I live with my husband Mike and 18 year old daughter Gaby and I like to spend my time doing all sorts of crafts. I love to fika (a Swedish word meaning stopping for coffee and cake)!

Ioannis Akermanidis

My name is Ioannis. I'm 26 years old,i am from Greece and I have been a member of the non-profit organisation "Karkinaki" since 2022. In 2009 got diagnosed with Non-Hodgkin lymphoma. My experience as a patient, made me choose to study nursing and currently I'm working as a Pediatric Intensive Care Unit nurse.

IG: ak_er_man

Iva Korovic

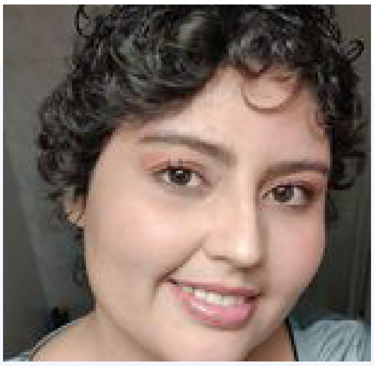
I am Iva from Montenegro, I am a double time survivor and currently a student of International Relations and Political Science at the University of Montenegro. I speak 6 languages, and enjoy reading, creatively expressing myself, cooking and travelling. Apart from studying and my other interests, I took on the role of a Young European Ambassador (YEA) whose key areas are Arts & Culture, Human Rights and International experiences.

IG: ppoisonnivy

Karen O’Neil

My name is Karen. I was diagnosed with acute myeloid leukaemia as a teenager in 2008. I was treated in a paediatric unit. Since then, I have remained involved with a number of national organizations involved in CAYA cancer care provision. I subsequently went on to study medicine and am currently working as a paediatric doctor in Dublin.

TW: Karen_M_ONeill



Lissandry Analia Acosta

My name is Lissandry and I live in Ghent. I’m 26 years old.

TW: AcostaLissandry
IG: Lissandry.a

Lucie Štrublová

I am 31 years old, I have a degree in nutrition and I work in an outpatient clinic for late effects as a nutritional therapist, I do research and I have a little 3-year-old daughter Anita at home.

Magdalena Jaworska

I'm good at promotion and communication, especially in sport. I'm a cancer survivor and I love paella. Organized chaos is kind of my thing.

TW: Madzia_Jaworska
IG: madzioska.j

Marie-Therese Gubi

My name is Marie. I'm 20 years old and currently studying medicine near Vienna. I would describe myself as a motivated, disciplined and focused young woman, who likes to work in a team and to achieve goals together as a team

Mariosa Grace-Churchard

I'm Mariosa, I'm 25 a cancer survivor, board member and treasurer of CanTeen Ireland. I can't wait to meet other people and hear about other people's experience and help create ways for people to transition from surviving to living.

Massimo Guglielmi

Massimo Guglielmi, born and raised in Italy by an Italian family, attended highschool and currently university. During my last year of highschool, at the age of 17th was diagnosed with cancer, in 2 years I fully recovered.

Matteo D’Abrosca

My name is Matteo D’Abrosca, I’m 21 and I’m Italian. I have been suffering from and have been battling Hodgkin’s lymphoma since the age of 13. I had two recurrences and finally a transplant, going through very difficult moments and, despite this, I had the strength to make known the harsh reality of pediatric oncology in Italy, Europe and the rest of the world, having the opportunity to make my experiential experience in all the Italian institutions: from the President of the Republic to the highest offices of the state. In Europe, among other things, I was welcomed by the top management of the Commission and the European Parliament; I was External Assistant to the European Commissioner for Welfare and Health Vytenis Andriukaitis. In truth, my goal is to bring a voice to those who feel lost and abandoned by the institutions; to those who feel alone, in order to communicate sincere hope. Later I became an assistant of the Italian government, I dealt with disability policies and safeguarding the rights of Italian pediatric oncology. In 2019, given my international successes, I was awarded at the White House for social commitment and the defense of human rights towards children with cancer, by the 45th President of the United States of America Donald Trump.

TW: matteo dabrosca
IG: matteo dabrosca

Luigi Oliviero

My name is Luigi Oliviero, I am Italian and I am Matteo D’Abrosca’s caregiver due to his illness. My 2-year-old son also had leukemia and is being treated in pediatric oncology in Rome. It will be a great honor to accompany Matteo given his disability and to be able to be part of this large family at European level since I experienced my son’s cancer.

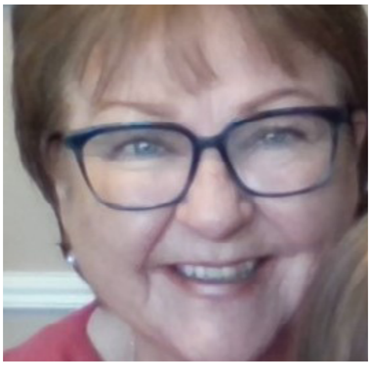
Michael Severinac

Cancer survivor, leader of the Croatian survivors group, patient advocate.

Nicola Unterecker

I have a creative but chaotic mind and will forever be a kid at heart. Partially grew up in the US but now live in southern Germany with my husband and cat, where I work in forestry and environment protection. I'm a morning person and even I don't like it, I also don't like coffee or the color pink.

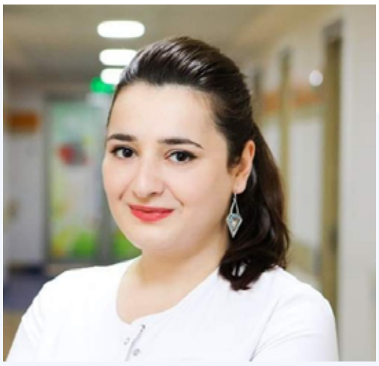
IG: nickipleeeeease



Patricia McColgan

Our son Rory was 14 when he was diagnosed with a brain tumour - he's 29 now and enjoying life. He's my inspiration for my advocacy work with Childhood Cancer Ireland for our CAYA and survivor community. In Sept we'll host our 3rd annual CAYAS conference in Dublin

TW: ChildhoodCanIre



Ruzanna Papyan

I am pediatric oncologist from Pediatric Cancer and Blood Disorders Center of Armenia, Hematology Center after prof. Yeolyan. From 2019 I am working as Assistant Professor at the Department of Pediatric Oncology and Hematology at Yerevan State Medical University and lead the Musculoskeletal Multidisciplinary Working Group, Pediatric Cancer and Blood Disorders Center. From 2022 I will also work as Clinical Research Physician at Immune Oncology Research Institute. From 2019-2021 I was studying at Harvard University, Harvard Medical School, Postgraduate Cancer Research Program. Currently I am Ph.D. candidate at YSMU, and my topic of research is soft tissue and bone sarcomas among children and young adults.

TW: ruzanna_papyan

Sara Lassfolk

Two time acute leukemia survivor, I am now involved in ` bettering the treatment of past, current and future cancer patients in Finland by being active in patient panels and associations. I am a certified peer support sponsor on local and national level as well as the vice-chair of Young Cancer Finland.

Sophia Sleeman

Sophia Sleeman (1993) works for the Dutch AYA 'Young & Cancer' Care Network, contributing to the improvement and dissemination of age-specific health care for cancer patients between 18 - 39 years old. In addition, she's a former board member and advocate at the Dutch patient organisation Stichting Jongeren en Kanker and a Youth Ambassador for ECL (Association of European Cancer Leagues). She got diagnosed with Non-Hodgkin's Lymphoma at the age of 18.

TW: SophiaSleeman

Sonia Silva

33 year old Breast Cancer Survivor based in Portugal; Feminist; Part-time singer; Brunch & Mimosas are life!

IG: sds136

Tiago Pinto da Costa

Portuguese childhood cancer survivor and patient advocate. Active member of ACREDITAR and CCI-Europe Survivorship Pillar. Also, CCI-Europe Committee Member.

TW:tiagoampc
IG: tiagoampc

Tim Van Hoorenbeke

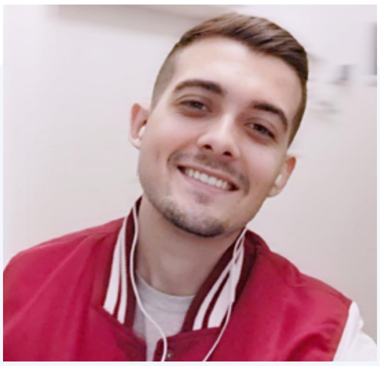
Hi my name is Tim, I am 27 years old and live in Antwerp Belgium. I am very excited to meet other AYA's from across Europe as I am already heavily involved with Kom Op Tegen Kanker (a Flemish organization) for better AYA care.

TW: timvanhoorenbeke

Vassilios Papadakis

Dr Vassilios Papadakis following MD (University of Athens) trained in Pediatrics and Pediatric Hematology-Oncology in the USA. Research activities involved transplantation, CNS tumor megatherapy and late effects of cancer treatment. He is Board Certified in Pediatrics and Pediatric Hematology-Oncology. Returning to Greece, he worked at Agia Sofia Children's Hospital in Athens, at Director's tier since 2011. PhD Degree referred to growth and gonadal function in children treated for Hodgkin's Lymphoma. Current research activities involve Neuroblastoma, Leukemias, Lymphomas and Histiocytic Syndromes and Long-Term Outcome of children treated for malignancies. Clinical practice involves the full spectrum of Pediatric Hematology – Oncology. He is leading the SIOPEN Quality-of-Life/Long-Term Outcome Committee and is the Scientific Advisor /Medical Doctor of the Make-A-Wish Foundation Greece. In parallel, he is married and has grown two young men, aged 28 and 31 years, computer science and mechanical engineers, but he cannot allocate enough for music and photography.

IG: vpapadakis___12345



Victor Girbu

Was in a relationship with cancer from 1994 to 2010. It didn't work out, so we broke up. 16 years gone to waste.

TW: VictorGirbu

Vanesa Karaivanova

My name is Vanesa. I am a cancer survivor from Sofia, Bulgaria. I was diagnosed with leukemia when I was six years old. Last few years I have been volunteering in the Association 'Children with Onco Hematological diseases'. I am also part of the Survivorship pillar I'm CCI-Europe.

IG: vanessa.karaivanova

Wilhelmina Plieger

Born in the Netherlands, mother of 3 children. Studied law at the University of Leiden. My son was diagnosed with Burkitt lymphoma at the age of 4. For 4 years patient advocate for the Dutch Childhood Cancer Organisation.

TW: Willemijn Plieger
IG: Willemijn Plieger

Brad Gudger

A two-time cancer survivor, Brad is one of Youth Cancer Europe's Steering Committee members, and the Founder and Director of Alike. Alike is an innovative charity created to combat loneliness and isolation caused by cancer. Established through lived-experience and inspired by YCE, Alike aims to achieve their mission by developing digital communication tools and technology. Brad works with the UK's Department of Health and Social Care and NHS England to shape Children and Young People's (CYP) health policy and ensure the voices of patients and communities are consulted during ministerial and leadership decision-making. He is Vice-chair of the National Academy for Social Prescribing and a member of the NHS Clinical Entrepreneur Programme Board. He has previously worked as a youth representative to the United Kingdom's Mission to the United Nations, and has been a Young Technical Advisor for the World Health Organization.

TW: BradGudger
IG: BradGudger

Katie Rizvi

Katie is a founder of Youth Cancer Europe, an advocacy network for young people with cancer shaping European policy. She is a member of the EORTC Group of Patient Experts and the Patient Advisory Committee of the European Cancer Organisation. Since 2016 she is a member of the Children's Medicines Working Party of The European Forum for Good Clinical Practice. For two terms she served on the Board of Directors of PanCare, a multidisciplinary pan-European network for the study of late effects of childhood cancer therapy. In 2002 she set up the Little People Children's Cancer Charity in Romania that provides daily psychosocial support services for Romanian childhood cancer patients in the clinical setting and peer-support to young people in after-care through online & residential programmes.

TW: katie_rizvi
IG: katierizvi

Carina Schneider

Today a passionate patient advocate, Carina was diagnosed with Ewing's Sarcoma at the age of 17. Experiencing the lack of adequate long-term follow-up care, she became active in patient advocacy in 2009. In 2017, she was part of the group of survivor-representatives from across Europe who launched the survivors-network within CCI Europe. Later that year, she joined the CCI Europe Committee. Carina is a psychology graduate and has worked in paediatric oncology since 2013, first in the Austrian Childhood Cancer Organisation as project manager and later at the Medical University of Vienna as research coordinator in the psychosocial team of the Paediatric Neurooncology Department. In January 2022, she became CCI Europe's Managing Director and works, together with a committed team, dedicated Committee Members and patient advocates from all over Europe for a better future for children, adolescents and young adults, as well as their families, who are affected by cancer.

TW: Cari_Schne
IG: cari_schne

Jaap den Hartogh

I have worked since 2021 in the Princess Máxima Center on survivorship issues. Before I worked a long time at the Dutch Childhood Cancer Organization. I'm married to Janice, and we have two children. I love to ride my bikes and play my guitars!

TW: jaapdenhartogh
IG: jaap_dh

Jeroen te Dorsthorst

My name is Jeroen te Dorsthorst, I work as a project manager for PanCare. I'm involved in the PanCare projects PanCareFollowUp and PanCareSurPass as well as UNICA4EU. Within EU-CAYAS-NET I will focus mainly on T3.5 regarding late effects and Long term follow up care.

Jikke Wams

I am a PhD-student in the Princess Máxima Center in Utrecht, the Netherlands, mainly working on the development of an international clinical practice guideline for the transition of child-centred to adult-oriented care for childhood and adolescent cancer survivors. I am 28 years old and I live in a small town nearby Utrecht. I am very involved with my hometown and active in local politics as a city councillor. I love being outside on a long walk or bicycle ride. I also enjoy gardening and do-it-yourself projects in and around my house.

Anita Kienesberger

Pediatric oncology nurse, patient advocate, CCI Europe chair

TW: Akienesberger

Zuzana Tomasikova

(*1986, Slovakia) • CCI Europe committee member and co-lead of the strategic pillar on Survivorship • Actively involved in survivors community since 2007 Former osteosarcoma patient • Manager of the Competence centre for Survivorship issues by Childhood Cancer Switzerland • Active patient advocate • professional background in Chemistry/Materials Science 2007-2015 active in different roles and with different responsibilities in Austria: peer mentor, co-organiser, regional and national co-leader and patient advocate Since 2012 also involved at the international level within CCI and CCI Europe Meanwhile responsible for the long-term follow-up and survivorship topics in the national umbrella organisation in Switzerland, among others for the development of the survivors' community on the national level as well as for raising awareness about survivorship issues. Actively involved in international projects with different stakeholders such as PanCare and SIOP Europe, regularly invited speakers in national and international meetings across Europe and co-organisator of the programme for the international conferences.

Barbara Brunmair

As a biologist, I have a life science background. I did my Master´s and PhD at the Medical University of Vienna, and my research focus was on cell metabolism at the Department of Medicine III, Endocrinology & Metabolism. From 2010 until Jan 2023, I worked as a Project- and Science Communications Manager at the St. Anna Children's Cancer Research Institute (St. Anna CCRI). I am especially happy to be part of Childhood Cancer International-Europe since February 2023. I have had the pleasure of working with them in previous collaborations and am now looking forward to being a true part of the team as their EU Projects Coordinator.

TW: BarbaraBrunmair
IG: brunmairbarbara

Šarūnas Narbutas

Diagnosed with a type of rare blood cancer (CML) at the age of 18 - that is 16 years ago. Still taking medication daily, not in a remission, but very close to it. In patient advocacy for over a decade. Co-founder and Chairman of YCE, Chief Advisor to POLA, leading WP2 - the Network Platform. Background in law, life sciences and health policy. Passionate about the potential of this network - finally we have means to create an EU level impact.

TW: lietuvai

Simonas Petkevičius

Managed the creation of the platform beatcancer.eu, doing bits of SEO and, now, maintaining it so that everything would run smoothly.

Begonya Nafria

Patient Engagement in Research Coordinator - PhD Candidate

TW: begonyanafria

Ulrike Leiss

Clinical Psychologist and Research Associate, specialized in the field of pediatric psycho-oncology and pediatric neuropsychology. She has been working at the Pediatric Neuro-Oncology Unit of the Comprehensive Center for Pediatrics of the Medical University of Vienna since 2001, both in the field of inpatient psychosocial care and in (long-term) follow-up care. There, she coordinates the COPEgroup, a team of interdisciplinary psychosocial professionals. Her focus areas in clinical care and research are: development and implementation of psychosocial standards, communication, education and career support, neuropsychological late effects/ therapy, and PPIE. She is a member of the SIOPe Psychosocial Working Group and the SIOPe Palliative Care Working Group.

TW: UlliLeiss

Johan de Munter

Johan De Munter is currently working as a nurse manager at the University Hospital Ghent Cancer Center and president of EONS. He has been a nurse in oncology-haematology for 23 years. He specialised and obtained a postgraduate degree in pain management and oncology. He continued to specialise by a postgraduate certificate in Teenage/Young Adult Cancer Care at Coventry University(UK), and last a postgraduate degree in leadership. He is a board member in the Majinhuis, a community support home for people affected by cancer. He is also a member of the steering committee and a lecturer on the Flemish training program for adolescents and young adults, and frequent guest lecturer in various courses. He is co-chair of the Flemish strategic AYA movement advisory group, an active member of the Belgian Haematology Society nurses committee, a member of the SIOP Europe AYA Committee, and a member of the Belgian Federal Council of Nursing.

TW: Jdmunter1

Urska Kosir

Cherine Mathot

I am a childhood cancer survivor which left me partially disabled, I am adopted from Sri Lanka to the Netherlands and an LGTBIQ+ person living in Amsterdam with my girlfriend. I currently work for PanCare for EU-CAYAS-NET and for the Dutch Childhood Cancer Association. I am an advocate for diversity and inclusion, my interest lies in psychosocial wellbeing and I am very much invested in the support and empowerment of survivors of childhood cancer..

IG: c.for.diversity

Helena van der Pal

I am Helena van der Pal, I am an internal medicaine Late Effects specialist in the Princess Maxima Center. I am also the previous chair of PanCare and involved in the research PanCare projects.

Anna-Elina Rahikainen

I'm Anna-Elina from Helsinki, Finland – both an AYA cancer survivor and a health care professional working with AYA cancer patients. My professional background is in Occupational Therapy, Psychosocial Rehabilitation and Service Design. I started the AYA cancer movement in Finland by organizing a Fuck Cancer campaign in 2016 together with other young adults affected by cancer. Since then, I've developed cancer services for young adults both working for an NGO and in the public sector. Now I work as a Project Manager and Service Planning Specialist at HUS Comprehensive Cancer Center. I'm in charge of the AYA Cancer Program and work as a coordinator of our hospital's AYA patient advisory board. I'm also leading the national AYA Cancer Network of Finland.

TW: anskurahikainen
IG: anskurahikainen

Rebekah Laura Lindores

I'm Bekkah, I'm 20, I love singing, horse riding and shopping!

Alex Docita

Hi there, I'm Alex, the photographer/videographer. I'm excited to be able to contribute with my work for this event. When I'm not behind the lens capturing unforgettable moments, you can find me planning my next adventure or cracking jokes with friends. I'm a big fan of spontaneous trips, great company, and beautiful sunsets. I thrive on new opportunities and enjoy collaborating with other creative individuals. Oh, and a fun fact about me - I may be tall, but I've got an even bigger sense of humor.

IG: alex.d0

For more information please see the event programme and other details on www.beatcancer.eu

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the European Union

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