

Press Release

Young cancer survivors in the driving seat: Ambassadors of the European Network of Youth Cancer Survivors meet in Vienna to discuss insufficient support after cancer treatment.

(Vienna, 24.11.2023) **Life doesn't just go on as normal after cancer treatment. This is a reality that most survivors of childhood, adolescent and young adult cancers have to face. In a unique EU-funded network initiative (EU-CAYAS-NET), young cancer survivors from all over Europe are coming together to create the conditions for meaningful change. They aim to reduce inequalities and enable more comprehensive, personalised care so that no young person living with and beyond cancer is left behind.**

After five years without a relapse, cancer patients are discharged and considered as cured. However, cancer at a young age leaves its mark: Those affected in childhood, adolescence or young adulthood have a higher risk of treatment or disease-related late or long-term effects. Apart from a few flagship clinical centres scattered across Europe, urgently needed support for a significantly growing target group is not widely available. As young cancer survivors will spend the rest of their lives dealing with late effects and the fear of relapse or recurrence of cancer, they also urgently need targeted psychosocial support. In addition, surviving such a serious illness comes with difficulties in finding a job and other economic barriers, such as with problems getting a loan or insurance.

"Cancer is not over when treatment is over. Certain issues accompany you throughout your life, whether just physical or psychological. Those affected need a public voice and peer support so they know they are not alone and can learn from the experiences of others." (Hannah Gsell, EU-CAYAS-NET Ambassador)

EU-CAYAS-NET: A network of Survivors for Survivors

For this reason, many cancer patient representatives from across Europe are rolling up their sleeves to close the gaps and take concrete action to address the unmet needs and rights and improve the quality of life of children, adolescents and young adults living with and after cancer (CAYAs). The glaring shortcomings were also recognised by the European Commission, which has taken numerous measures as part of Europe's Beating Cancer Plan. One of these is the funding of EU-CAYAS-NET, the first multinational network dedicated to survivorship and **solely led by patient advocates**, whose Ambassadors are currently meeting in Vienna.

Since September 2022, the Network of Youth Cancer Survivors has been working very effectively on building a communication platform for peer support (<https://beatcancer.eu>) carrying out research, as well as developing social media campaigns, webinars, policy recommendations and events on the topics identified as

most pressing: quality of life, care for adolescent and young adult patients, equality, diversity and inclusion.

"When I was diagnosed with this difficult disease, I quickly realised that society has these unrealistic expectations of cancer patients. They want them to be positive all the time in the midst of difficulties. I joined the network in the hope that we can improve the lives of other young cancer patients and survivors." (Sonia Silva, EU-CAYAS-NET Ambassador)

Network Ambassadors: the gold & soul of the initiative

Ambassadors of the European Network of Youth Cancer Survivors are integral to communicating about, and advocating for, survivorship-related issues at national levels, providing a link between European and national activities. They are driven by a palpable sense of mission and passion as they can speak about their cancer in the first person. At the Youth Cancer Survivors Ambassador Training Event in Vienna, Austria (<https://beatcancer.eu/events/>), 65 Ambassadors came together to learn about the project, practise patient advocacy and everything associated with it in order to stand up strongly and confidently for the network. Going forward, this resilient group of survivors, ready to make a difference, commits to continue working towards meaningful change to reduce inequalities and create more comprehensive, tailored care so that no young person with lived experience of cancer is left behind.

Further events will follow next spring, at which we will present initial results on the project topics of quality of life, AYA care, equality, diversity and inclusion for this target group. Stay tuned!



Photo: Ambassadors of the European Network of Youth Cancer Survivors meet in Vienna to discuss insufficient support after cancer treatment.

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About the project

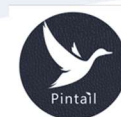
EU-CAYAS-NET is a 2-year project led by patient advocates under one of the Flagship Initiatives of Europe's Beating Cancer to build a "European Network of Youth Cancer Survivors" and to create a knowledge centre and interactive platform for social networking. EU-CAYAS-NET fosters social networking, peer-support, knowledge-exchange, and will improve:

- the quality of life of survivors – including mental health, education & career support,
- follow-up care and transition from paediatric to adult health care,
- the care for adolescents and young adults (AYA) with cancer, as well as
- Equality, Diversity and Inclusion (EDI) along the whole treatment and survivorship trajectory.

The communication platform www.beatcancer.eu is an interactive hub where survivors can get answers to questions, share with like-minded people and last but not least have fun. It is a safe place to share, learn and grow. We welcome everyone dealing with childhood, adolescent and young adult cancer. This includes not only cancer patients, survivors and their caregivers themselves, but also stakeholders from healthcare, research or policy.

Project coordination: The project is jointly coordinated by two major patient/survivors umbrella organizations [Childhood Cancer International – Europe](#) (CCI-E, Carina Schneider, Anita Kienesberger) & [Youth Cancer Europe](#) (YCE, Katie Rizvi, Šarūnas Narbutas)

Beneficiaries & Associated Partners: Leading organisations from 18 countries active in the field (9 project beneficiaries and 28 associated partners) map resources for young cancer patients, survivors and their caregivers, create new European guidelines and empower cancer survivors to advocate for their rights and needs.



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