

ENTYAC Newsletter

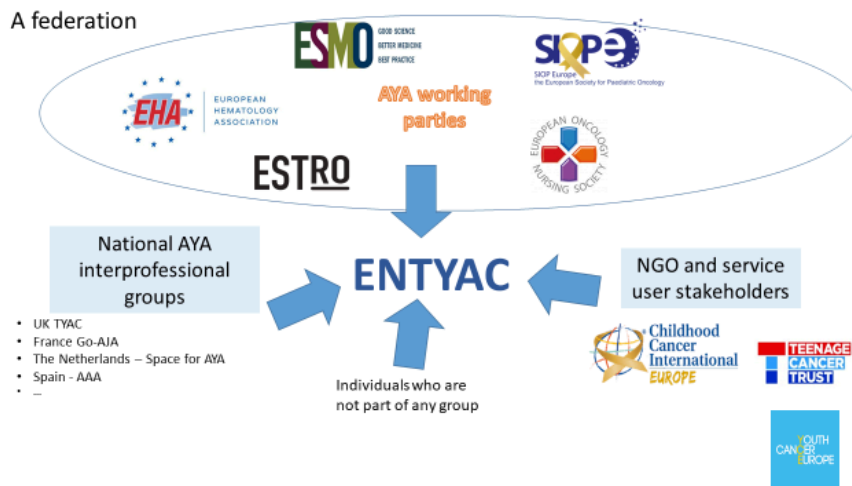
We last updated in detail in 2022. We have been busy and wanted to update you all further.

The place where all European cooperative projects will be realised, mapping progress, from different clinical, geographical and cultural perspectives, in age-specific cancer care across the diverse European landscape and share that data with policy-makers to seek improvements

A European Network for Teenagers and Young Adults with Cancer
ENTYAC

A federation where existing health care professional societies, national AYA professional groups, Non-Governmental Organisations (patients, advocates and their families) that have a stake in AYA cancer can co-operate and grow

ENTYAC plans and progresses projects that can improve care and outcomes for TYA with cancer, by bringing organisations and individuals together.



The leadership group for ENTYAC includes representatives of the national TYA organisations and international cancer professional societies, NGOs, charities and patient organisations. The current 14 members of this leadership group are:

Johan De Munter (BE), Andrea Ferrari (IT), Leila Gofti-Laroche (FR), Assia Konsoulova-Kirova (BG), Valerie Laurence (FR), Katie Rizvi (RO), Carina Schneider (AT), Dan Stark (UK), Beate Timmermann (DE), Josef Vormoor (NL), Anna Castleton (UK), Ivana Bozovic (RS), Ashley Gamble (UK), Anita Kienesberger (AT).

Huge thanks to Anne Blondeel from SIOP Europe for her excellent support.

Many thanks to Marie Balsat who has moved on from this committee. A very warm welcome to newest members Beate Timmermann (ESTRO) and Leila Gofti-Laroche (go-AJA).

ENTYAC have been very active this year.



During 2022 ESTRO have joined our collaboration, represented by Beate Timmermann. Beate is the Director of the Clinic for Particle Therapy and Head of the West German Proton Therapy Center Essen (WPE) has been nominated by the ESTRO to represent the European radiation oncologists in the ENTYAC Steering Group and to establish an AYA working group within the ESTRO. She is committed to promote education and is director of the ESTRO Course “Paediatric Radiotherapy”. Prof. Timmermann is also actively involved in the German sarcoma and brain tumour studies. She is member of the Executive Committee of the PROS (International Society for Pediatric Radiation Oncology) promoting the world-wide standard of excellence with respect to radiation oncology in the care of children and adolescents with cancer. In clinical practice, WPE is the leading institution in Europe to irradiate children and young adults with about 350 children annually receiving proton beam therapy, particularly for sarcomas and CNS tumours. Thus, she will make a valuable contribution within the leadership group and, she is looking forward to this honourable and important assignment. As an early contribution, she has offered to host a meeting of the ENTYAC group in 2023 in Essen.

We are also delighted that the European Haematology Association (EHA) joined ENTYAC recently. Their AYA work is led by Josef Vermoor and Anna Castleton. [They are putting their AYA taskforce together and will update us all soon.](#)

ENTYAC have completed a survey of NGO activity dedicated to AYA in Europe, working with our partner NGOs. This identified details of 39 AYA-dedicated charities and NGOs in 14 EU nations. We plan next to work more closely with them, if they agree!

ENTYAC have provided educational content in 2022 to support other meetings

- [An ENTYAC half-day in Milan in September 2022](https://www.fondazione-menarini.it/Home/Eventi/Get-up-stand-up-for-ayas-with-cancer/810/Presentazione) entitled ‘Get up, stand up, for AYA’ kindly sponsored by the Fondazione Menarini. (<https://www.fondazione-menarini.it/Home/Eventi/Get-up-stand-up-for-ayas-with-cancer/810/Presentazione>) This included presentations on epidemiology, services, clinical trials, international societies, patient and carer round-tables and perspectives, NGO and charity perspectives, the right to be forgotten, sexuality, and genomic cancer medicine. Professor Barr from Ontario and Dr. Maru from Kobe were key global guest speakers.
- Contributed to an ESMO/Hellenic Society of Medical Oncology educational course in Athens where ENTYAC provided training on epidemiology, difficult cases, setting up AYA cancer services, site-specific cancer management in AYA and cancer clinical trials.

If you would like to seek support with your AYA cancer educational activities, do please ask – we can try to help.



SPOTLIGHT on Go-AJA



Website <https://goaja-fr> ; twitter @Go_AJA_Go

Go AJA also wants to let you know about their dynamic year in 2022:

- Supporting national AYA network : now 22 AYA teams over French territory with 2 new teams in 2022



- Creation in 2022 of a national Inter University degree: « AYA and cancer » , 20 students yearly.
- Promoting research in AYA field, with a yearly GO AJA national research grant launched in 2021 (200k€), going on in 2023.
 - o OnKO-Tips&Tricks, Strasbourg : Effectiveness study on quality of life criteria of a digital application on any cell phone allowing daily follow-up, implementation of an ETP program and a direct link with the nurse coordinator of units specifically dealing with adolescents and young adults diagnosed with cancer.
 - o GYN-AJA, Lyon : Gynecological follow-up and management in AYAs cancer survivors : a national health insurance data study.
- The evolution of the regulatory framework which reinforces the attention that health care structures must pay to children, adolescents and young adults (ten-year French Cancer Plan 2021-2025 and Decrees of authorisation in cancerology published April 2022).

- Discussion with health authorities and with National Cancer Institute InCA about MTD and inter-regional AYA pathways of care.
- They held the 2nd International Course on Sarcoma in Children and the AJA from 12 to 15 December 2022 in Paris.
- National recommendations in progress in a newly established co-operation with AFSOS (the French Association dedicated to supportive cancer care)- examining onco-sexology, fertility preservation, therapeutic education, adapted physical activity (with educational and professional integration).
- Celebrating their 10th anniversary! The update of the French epidemiological data 2000-2016 was published in J Adolesc Young Adult Oncol (2021).

We have some large and exciting new research projects together:

- Strong – AYA: Led by Professor Winette van der Graaf and Dr. Olga Husson from Amsterdam (<https://cordis.europa.eu/project/id/101057482>)

STRONG-AYA began in October 2022, as an interdisciplinary, multi-stakeholder European network to improve healthcare services, research and cancer outcomes for people aged 15-39. AYA-specific healthcare services are scarce and vary across Europe. AYA-care and research needs patient-centered data and collaboration among patients, healthcare professionals, scientists, and policymakers, data science and registries. We will set up a value-based healthcare research ecosystem providing data-driven, interactive data visualization tools, in co-creation with all stakeholders. The project objectives are:

- Development of a Core Outcome Set (COS) that should be measured in every study about AYA.
- Measure the COS in FR, IT, NL, UK, PL.
- Establish national collaboration infrastructures that use outcome data to influence clinical decision-making.
- Develop data-driven analysis tools to process and present relevant outcomes, feeding those back to AYA cancer patients, healthcare systems, and policy-makers.
- Expand and sustain in the future.

- Joint Action on Network of Expertise ('JANE'): Led by Anna-Lisa Trama, Milan. (<https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/how-to-participate/org-details/999448037/project/101075328/program/43332642/details>)

The AYA part in this Joint Action on Network of Expertise (JANE) will be to do the preparatory work needed to launch a future Network of Excellence in AYA cancer. Over 2 years, the collaboration (involving Italy, Belgium, France, Greece, Malta, Romania, Slovenia and Spain) will define the mission/objectives (care, research, education, etc.), define a design, best governance structure, and selection criteria for future participant organisations and individuals. ENTYAC plans to be a key part of this discussion and future development of our network.

- European Network of Youth Cancer Survivors ("EU-CAYAS-NET"): Led by CCI Europe and Youth Cancer Europe. (<https://beatcancer.eu/>)

This European Network of Youth Cancer Survivors is a 24-month project that started in September 2022, bringing together 10 beneficiaries and affiliates and 28 associated partners from 23 European countries, to improve the quality of life of children, adolescents and young adult cancer survivors. We will do this by designing and developing a network platform to facilitate social networking,

provide peer support, have a virtual co-working space and repository of relevant content created during the project. The project addresses Quality of Life, Adolescent and Young Adult (AYA) Care and Equality, Diversity and Inclusion (EDI). The activities of the project include peer visits, meetings, training, virtual co-working, social media campaigns, webinars, policy recommendations and national and international events.

In 2023 ENTYAC plan

1. To hold a business meetings, hybrid between in-person and on-line. We hope this will be in Essen in Q3 2023. We will share our future plans with all of you, and involve you further where you wish. If you are interested to come to this, please [follow this link](#) to register your interest.
2. To set our ENTYAC strategy for 2023-26 and identify the work we propose to complete. We will make proposals in advance, and discuss them at the Business meeting. These might be
 - a. Ways you would like to see ENTYAC develop next, for you, patients, and your colleagues.
 - b. Projects for TYA with cancer that you know about, that are working well locally and should spread more widely across Europe.

If you have proposals for strategic projects we should complete, let us know by email to Anne- (Anne.blondeel@siope.eu).

3. To see in print the 2021 healthcare professional survey and disseminate the 2022 NGO survey.
4. To identify other partners in ENTYAC. This might include other international organisations such as EORTC, ECO, EBMT. It may include a wider range of NGOs. It might also include a larger group of national or regional TYA-dedicated societies.

Other upcoming AYA events in 2023

- AYA Congress in Palm Beach California, USA, June 20-22nd 2023
<https://ayaglobalcancercongress.org/>
- SIOPE AYA Committee session at the SIOP Europe Annual Meeting in Valencia, 8-12 May 2023
<https://siopeurope.eu/> – Top speakers will discuss the feasibility and clinical value of whole genome sequencing for AYA from cancer diagnostics to cancer predisposition.
- SIOPE AYA - 2-Day Virtual Course for early career doctors, planned for September 2023 – contact anne.blondeel@siope.eu

Possibilities for 2024

An ENTYAC Academic congress?

Would you like to feature any of your work in this newsletter in future? If so, let us know!

For more information about ENTYAC, please contact anne.blondeel@siope.eu