



GdL Adolescenti

Andrea Ferrari

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Fondazione IRCCS Istituto Nazionale Tumori

Bologna, 23 aprile 2024



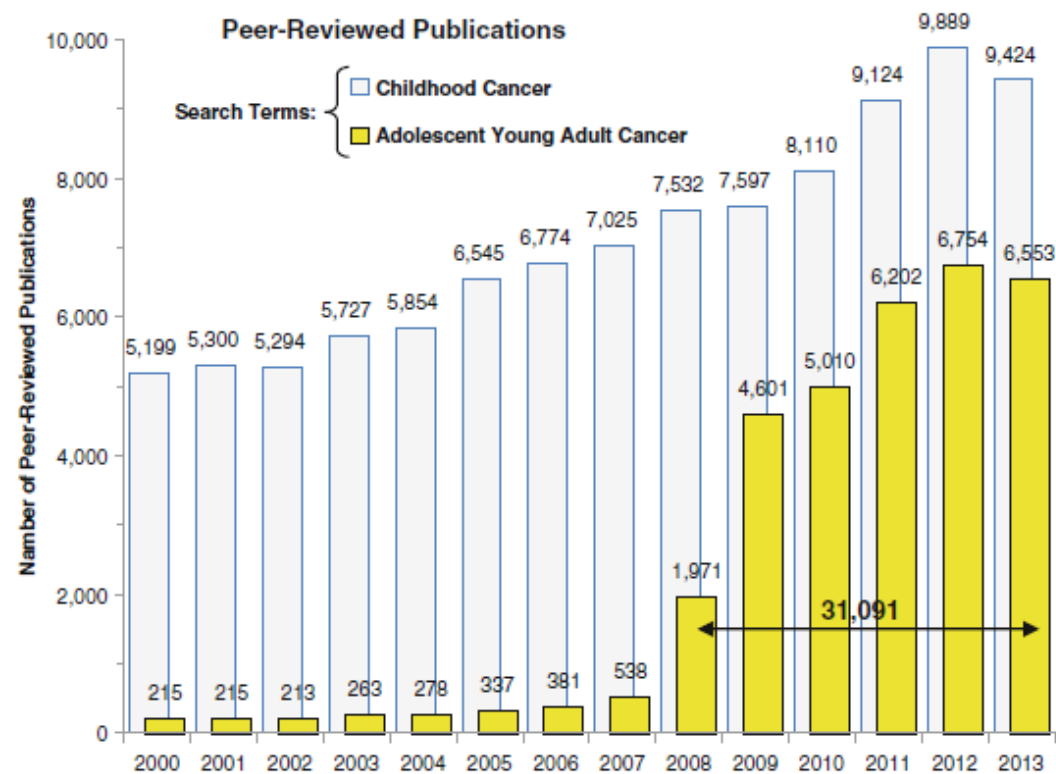
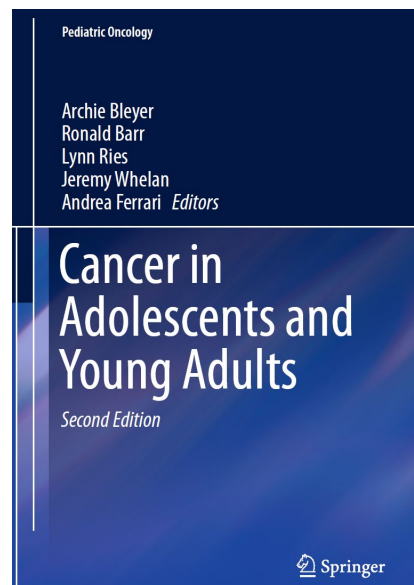
Il sottoscritto Andrea Ferrari

*ai sensi dell'art. 3.3 sul Conflitto di Interessi, pag. 17 del Reg. Applicativo
dell'Accordo Stato-Regione del 5 novembre 2009,*

dichiara

*che negli ultimi due anni NON ha avuto rapporti diretti di finanziamento con
soggetti portatori di interessi commerciali in campo sanitario*







YOUTH
PROGETTO GIOVANI

AIEOP Working Group for Adolescents



AIEOP-AIOM Working Group dedicated to AYAs



SIOPE AYA Committee



SIOPE-ESMO AYA Working Group



ENTYAC - European Network for Teenagers and Young Adults with Cancer

THE STRONG-AYA INITIATIVE
IMPROVING THE FUTURE OF YOUNG ADULTS WITH CANCER
HORIZON-HLTH-2021-CARE-05



EU-CAYAS-NET





“prima” Commissione Adolescenti AIEOP 2007



2014

ENTYAC - European Network for Teenagers and Young Adults with Cancer

2015 SIOPE AYA Committee



2016 SIOPE-ESMO AYA Working Group



“seconda” Commissione Adolescenti AIEOP 2018

GdL Adolescenti AIEOP 2020

Gruppo di Lavoro intersocietario AIOM-AIEOP dedicato adolescenti e giovani adulti 2021



2024

NoE AYA





GdL

**GdL in
Italia**

**GdL in
Europa**



GdL Adolescenti

- Andrea Ferrari, Milano
(coordinatore)
- Paola Quarello, Torino
- Titty Tornesello, Lecce
- Terry Perillo, Bari
- Giuseppe Milano, Roma
- Marco Spinelli, Monza
- Maurizio Mascarin, Aviano

Gruppo Allargato:

Marta Pierobon, Padova
Maria Speranza Massei, Perugia
Clerici Carlo Alfredo, Milano
Paolo Colavero, Lecce
Chiara Rutigliano, Bari
Luca Lo Nigro, Catania
Zama Daniele, Bologna
Luca Coccoli, Pisa
Elena Pagani, Monza
Massimo Conte, Genova
Virginia Livellara, Genova
Valentina Corsini, Pisa
Anna Fracchia, Torino
Elena Fabbri, Rimini
Samanta Nucci, Rimini
Anna Campello, Torino
Fabiola De Gregorio, Napoli
Pietro Soloni, Trento
Ilaria Puglisi, Bologna
Elena Legnani, Bologna

GdL

studi

GdL in
Italia

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Journal of Pediatric Hematology/ Oncology

ONLINE ARTICLES: ORIGINAL ARTICLES

How Did Adolescents With Cancer Experience the COVID-19 Pandemic? A Report From Italian Pediatric Hematology Oncology Association Centers

Zucchetti, Giulia Psy, PhD^{*,†}; Quarello, Paola MD, PhD^{*,†}; Ferrari, Andrea MD[‡]; Silva, Matteo DR[‡]; Mercolini, Federico MD[§]; Sciarra, Pierpaolo Psy[‡]; Guido, Antonella Psy[¶]; Peruzzi, Laura Psy[¶]; Colavero, Paolo Psy[¶]; Montanaro, Maria Psy^{**}; Taormina, Rino Psy^{††}; Micheletti, Maria V. Psy^{‡‡}; Solari, Federica Psy^{§§}; Perillo, Teresa MD^{||}; Paioli, Anna MD^{¶¶}; Canepa, Monica Psy^{###}; Migliozi, Camilla Psy^{***}; Zuliani, Livia Psy^{†††}; Solfa, Valentina Psy^{‡‡‡}; Bertolotti, Marina Psy^{*,†}; Fagioli, Franca MD^{*,†}

Salute è giustizia sociale

soleterre

Progetto “Salute è.....Inclusione Lavorativa”

Ricerca per la strutturazione di un servizio di supporto al reinserimento scolastico-lavorativo

QUESTIONARIO

Introduzione

Grazie per aver deciso di partecipare al Questionario del progetto “Salute è.....Inclusione Lavorativa” della fondazione SOLETERRE.

Il progetto si propone di conoscere, attraverso delle attività di ricerca, quali siano le principali difficoltà affrontate dai ragazzi e giovani adulti che hanno/hanno avuto il cancro. I servizi di supporto ritenuti più utili, con una particolare attenzione ai temi dello studio, della prospettiva lavorativa, perdita dell'occupazione e del reinserimento lavorativo nell'ottica di estendere l'offerta dei servizi ad oggi esistenti.

Il presente questionario è anonimo, i dati raccolti verranno trattati solo in modo aggregato.

Il Questionario è diviso in CINQUE parti, e può essere compilato in 15 minuti.



GdL

studi



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Studio InDiA

Studio sull'**I**ntervallo **D**iagnostico nei pazienti **A**dolescenti afferenti
ai centri AIEOP, confrontato con i bambini"

The power of art and the powers of adolescents with cancer: Age-specific projects at Italian pediatric oncology centers

Andrea Ferrari¹ , Teresa Perillo² , Giuseppe Maria Milano³, Matteo Silva¹, Chiara Rutigliano², Andrea Salvo³, Virginia Livellara⁴, Massimo Conte⁴, Luca Coccoli⁵, Elena Amore⁵, Marta Pierobon⁶, Francesco Vietina⁶, Elena Pagani Bagliacca⁷ , Marco Spinelli⁷, Maria Speranza Massel⁸, Valentina Massetti⁸, Elena Legnani⁹, Ilaria Puglisi⁹, Giulia Zucchetti¹⁰  and Paola Quarello¹⁰

Tumori Journal
1-9
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Nazionale dei Tumori
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DOI: 10.1177/030
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Figure 1. The adolescent patients of the Youth Project in the recording studio for the song 'Christmas Balls'. The video on YouTube went viral, with more 17 million views. The song became a hymn to shared values and profound sentiments like friendship, affection for other people, solidarity, and the feasibility of making something wonderful come out of even the most difficult situations. **[AQC-11]**



Figure 2. A girl of the 'Stranger Teens' project poses for the photographer with the jewelry she designed.

Eleonora – one of the girls involved in the project – tells us:

My collection is called 'Won'. 'Won' is the Korean term meaning 'the fear of giving up illusions to face reality'. It is the fear of realizing that life is not perfect. Life is like a flower: beautiful, colorful, and fragrant, but also delicate, fragile, and sometimes thorny. But it is unique. Like us. 'Won' is the fear of accepting being sick and fragile, of understanding that

is also the strength to face it all, to fight and win, just like the meaning the word 'won' takes on in English: I win.

Pisa

'Teen Freedom' is the name of the AYA project created at the pediatric onco-hematology unit of the Santa Chiara Hospital in Pisa. The football team that had formed to participate in the Winners' Cup planned to carry on and founded the Teen Freedom in 2019. Eleonora, one of the players, said:

The Winners' Cup is a metaphor of life: it doesn't matter if you fall down, if you lose the way, what really matters is never giving up. And if someone tries to come between you and your goal, you must only run like never before, straight to the goal. We are warriors, warriors that won the hardest battle ever.

Various creative writing workshops and 'Words on own experience'

I look to myself that book without having sometimes to know, for

Bari

'Temporary Department help teenagers self-image through the multifunctional courses, fashion photography beauty, and experience this sea lives. Pictures to capture unexpected strength'

Perugia

Social are Miss call boc

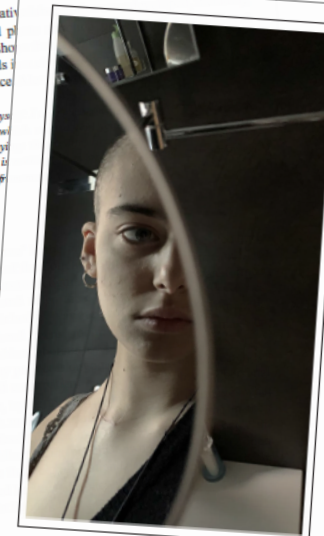


Figure 3. A young patient of '4youLAB' captures her feelings with her smartphone.

take into consideration the subjective perception of time and to perceive and tune in to the rhythms of others.

Genoa

Adolescent patients at the pediatric oncology department of the Gaslini Children's Hospital in Genoa, are involved in the 'Color Care' project, where they can tell their stories and emotions through various expressive forms including writing (free from the traditional rules of syntax), but also theatrical animation, improvisation, use of the body, music and color. These different methods help them to use their imagination in order to re-elaborate their illness. This lab creates a space for sharing, to overcome the idea of the cancer experience as an irreparable fracture with oneself and with others. Art and creativity can offer teenagers a new modality of narration of their story, a personal point of view that can be shared with others.

Bologna

Various AYA-specific initiatives are developed at the AIEOP center of Policlinico Sant'Orsola in Bologna, including a photography laboratory, make-up course, dance course (in which movement is used as non-verbal communication to manage physical and emotional concerns). In a currently ongoing project, young patients are working to create a sort of instruction manual with the aim to offer support and advice for their peers embarking on the same cancer journey (offering for example some 'survival tricks'), but also containing specific instructions for doctors, psychologists and nurses dealing with them. They have developed a list of recommendations for the staff, with 10 bullet points: 1) enter the room with a smile (we already have enough tears); 2) ask me how I'm doing (I am not my blood pressure or my white blood cell count); 3) listen to me (don't listen to my lungs, at least not only); 4) I'm not my disease, I am a person; 5) learn to be empathetic; 6) respect my feelings; 7) don't hide anything from me, I want to know; 8) never belittle me; 9) stretch your mind, not your muscles; 10) look into my eyes.

Summary

We believe there is a great value in all these experiences coming from different centers throughout Italy, highlighting the willingness of doctors and patients to build such creative projects together. These stories emphasize the worth of giving young patients novel creative ways to express themselves freely, as a key part of the process that may enable them to elaborate what happens when they are diagnosed with cancer.

Creative projects may have other different goals, i.e. a way for patients to share their difficulties with other young people going through the same experience, but also to find a sense of light-heartedness during their hospital stays, and regain a sense of future, working on projects expected to take several months (Table 1).

In these activities, our patients voice their courage and awareness of their condition, but also reveal their fragility (that often remains after completing their treatment too). Projects should therefore provide dedicated spaces and opportunities for socializing and recreation, but also 'protection', to help patients weather the storm of their disease. For this reason, we strongly believe that programs that bring together young people with cancer must be professionally organized and realized within the hospital.⁴⁹

Milano, Padova, Bari, Roma, Monza, Pisa, Bologna, Perugia, Genova, Torino

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1. get together	these projects gave young patients an opportunity to get together, both patients that are receiving treatment and those who have completed their course of therapy; patients share the difficult time of their treatment with other young people going through the same experience
2. live moments of normality and light heartedness	these projects gave patients an opportunity to live moments of normality, reminding them that before being a patient with cancer, they are teenagers; during meeting, they can find a sense of light-heartedness even in the middle of their hospital stays and cures
3. feel important	these projects gave patients an opportunity to feel important, working with professionals (this may be not an easy achievement, given that it is a critical time of their lives, when their self-esteem might be deeply damaged)
4. regain a sense of future	these projects gave patients an opportunity to regain a sense of future and longer-term planning, working on a project expected to take several months (their cancer obliges adolescent patients to abandon any plans and drastically change the way they think about the future; their time horizon can shrink to the day they will be discharged from hospital, or the start of their next cycle of therapy)
5. express themselves	these projects gave patients an opportunity to express themselves more freely: they need to tell their story, to themselves and others; talking about their disease and how they feel is of great importance in the process of elaboration of the trauma of the cancer diagnosis, in order to find the inner resources to answer to the question "Why me?". For the medical staff, these projects are like a precious window on the inner world of adolescent cancer patients, enabling them to better understand what they are really thinking and feeling, directly from them, as a complement of conventional methods for providing psychosocial support
6. talk to the community	these projects gave patients an opportunity to talk about themselves to the community (general population and mass-media, but also scientific community and scientific journal) to improve the awareness that even AYA can develop cancer, and that dedicated projects are needed. Young patients act as testimonials in programs designed to draw the attention also to the clinical problems of AYA with cancer



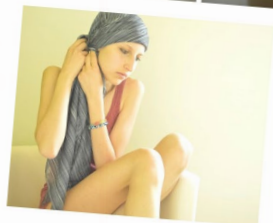
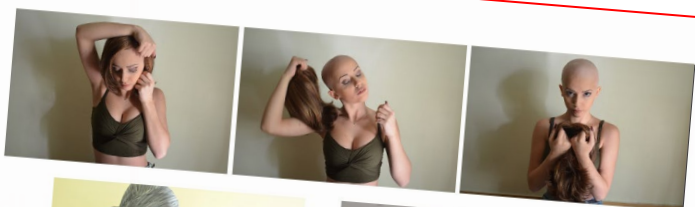


La bellezza dell'imperfezione

GdL

- Il progetto fotografico del GdL Adolescenti AIEOP coinvolgerà i centri nazionali coinvolti nel GdL e nella Winners Cup
- Scopo del progetto è creare una connessione tra i diversi centri in Italia, una rete di racconti visivi condivisi dai ragazzi e per i ragazzi
- I ragazzi sono invitati a produrre una fotografia che riesca a dare un senso a questo tema: *cosa è meravigliosamente imperfetto per te?*
- Una visione delle cose che trova il valore in ciò che è unico e autentico, un modo di vedere il mondo che ci invita ad apprezzare la sua imperfetta unicità dentro e fuori da noi, in cui ogni cosa, vista dalla giusta prospettiva, si illumina di una bellezza unica.

GdL in
Italia



"La ricerca della felicità: alcuni scatti esposti al PAC"

- Il mezzo fotografico, telefono o macchina fotografica che sia, pone i ragazzi in una dimensione di racconto e di ascolto, di scambio tra dentro e fuori di sé; con lo sguardo della fotografia è possibile appropriarsi di un linguaggio che va oltre le parole
- Il progetto si avvarrà della collaborazione di Alice Patriccioli, fotografa che già aveva coordinato il laboratorio fotografico de "La ricerca della Felicità" (Milano, 2016)
- Obiettivo del progetto è la realizzazione di una mostra di fotografie e di un catalogo/fanzine con le fotografie dei ragazzi di tutti i centri che aderiscono all'iniziativa. Le fotografie, stampate su pannelli mobili, saranno esposte durante la Winners Cup 2024 e gli eventi ad essa connessa.

<https://doi.org/10.1016/j.esmoop.2021.100096>



GdL *Cooperazione con altri GdL AIEOP*

**GdL in
Italia**

**GdL in
Europa**

La consapevolezza della cattiva prognosi

(progetto in comune con il GdL psicosociale)

SCARPONI, BERTOLOTTI, FERRARI

- *MODELLI COMUNICATIVI IN LETTERATURA: MONTANARO, POGGI*
- *LA COMUNICAZIONE DELLA PROGNOSI AL PAZIENTE: PERILLO*
- *LA COMUNICAZIONE DELLA PROGNOSI ALLA FAMIGLIA: BERTOLOTTI, MASCARIN, QUARELLO*
- *LA PERCEZIONE DELLA COMUNICAZIONE DEL PAZIENTE: CELLINI, SCARPONI*
- *LA PERCEZIONE DELLA COMUNICAZIONE DELLA FAMIGLIA: CELLINI, SCARPONI*
- *IL LUTTO PER UN AMICO/AMICA, COMPAGNI DI CLASSE: COLAVERO, TORNESELLO*
- *NARRAZIONI CLINICHE: BERTOLOTTI, MASCARIN, QUARELLO*
- *IL CONSENSO/ASSENSO: BLOM, CLERICI*



GdL

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11 Aprile 2024

Primo Focus sulla Biologia del Tumore negli Adolescenti

15:00 Introduzione	Lo Nigro L - Ferrari A
15:05 LLA	Conter V - Cazzaniga G
15:45 Rabbdomiosarcoma	Bergamaschi L + Gasparini P
16:25 Linfoma di Hodgkin	Mascarin M + De Re V
17:10 Neuroblastoma.	Livellara V + Mazzocco K
17:55 Closing remarks and Take home messages	Lo Nigro L - Ferrari A



GdL



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Adolescents and young adults with rhabdomyosarcoma treated in the European paediatric Soft tissue sarcoma Study Group (EpSSG) protocols: a cohort study



Andrea Ferrari, Julia C Chisholm, Meriel Jenney, Veronique Minard-Colin, Daniel Orbach, Michela Casanova, Gabriela Guillen, Heidi Glosli, Rick R van Rijn, Reineke A Schoot, Alison L Cameron, Timothy Rogers, Rita Alaggio, Myriam Ben-Arush, Henry C Mandeville, Christine Devalck, Anne-Sophie Defachelles, Beatrice Coppadoro, Gianni Bisogno*, Johannes HM Merks*

GdL

Winners Cup



GdL in
Italia



GdL in
Europa





GdL

Winners Cup



GdL in
Italia

GdL in
Europa

**SAVE
THE
DATE**



4-6 ottobre 2024



GdL

Collaborazione con FUV



Progetto #fattivedere

- workshop cinematografico e dibattito
- dal 2015, coinvolti 30.000 ragazzi delle scuole superiori
- mass media e approfondimenti

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10 sintomi a cui prestare attenzione

1. se hai febbre o febbricola da settimane senza una chiara spiegazione;
2. se hai un dolore, per esempio alle ossa o alle articolazioni, o in qualsiasi altra parte del corpo, che non ha un'altra spiegazione medica e che torna di continuo,
3. se hai un gonfiore o una tumefazione, per esempio ai testicoli o in qualsiasi altra parte del corpo, che non è chiaro da dove venga e che non passa da più settimane,
4. se da settimane sei molto stanco, senza una ragione chiara, e ti bastano anche sforzi lievi, come fare le scale, perché ti manchi il fiato,
5. se hai notato che un neo è cresciuto rapidamente di dimensioni, ha cambiato colore o forma, o ha sanguinato
6. se hai perso molto peso negli ultimi tempi, senza un preciso motivo,
7. se hai notato la comparsa di molti lividi senza alcun trauma evidente o facilità al sanguinamento (dal naso o dalle gengive, per esempio),
8. se hai dei linfonodi ingrossati (per esempio al collo, all'inguine, sotto le ascelle), che non fanno male e che sono presenti da più settimane, senza una causa specifica,
9. se hai spesso mal di testa, che tende con i giorni a peggiorare, o che ti sveglia di notte, o se hai riscontrato un rapido peggioramento della vista, o ti sembra di vedere doppio, o hai disturbi dell'equilibrio,
10. se ti sei accorto di sudare abbondantemente di notte, o hai spesso prurito intenso, o comunque hai sintomi che non capisci e che persistono.



Incontri con le scuole

Incontri in presenza

Nei mesi di febbraio e marzo sono stati organizzati 5 incontri, nel format del workshop cinematografico, nelle seguenti città:

- **6 febbraio: Milano**, Anteo Palazzo del Cinema, con l'equipe dell'Istituto Nazionale dei Tumori
- **28 febbraio: Roma**, Cinema Farnese, con l'equipe dell'Ospedale Bambin Gesù



#FATTIVEDERE_ Edizione 2024: i numeri

6 incontri: 5 in presenza e 1 webinar

Milano	228 studenti
Roma	168 studenti
Teramo	100 studenti
Venezia	162 studenti
Torino	285 studenti
Online	1688 studenti
Totale studenti che hanno partecipato: 2631	

12 ragazzi ex



#FATTIVEDERE_ Edizione 2025

Per la prossima edizione sono previsti 10 incontri:

- 9 incontri nelle seguenti città: Bari, Milano, Padova, Pisa, Roma, Teramo, Torino, Trento e Venezia
- 1 incontro online sulla piattaforma GotoWebinar

GdL

Collaborazione con FUV



GdL in
Italia

2023 – il ritardo diagnostico
2024 – il gap di arruolamento nei protocolli clinici
2025 - ...

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GdL

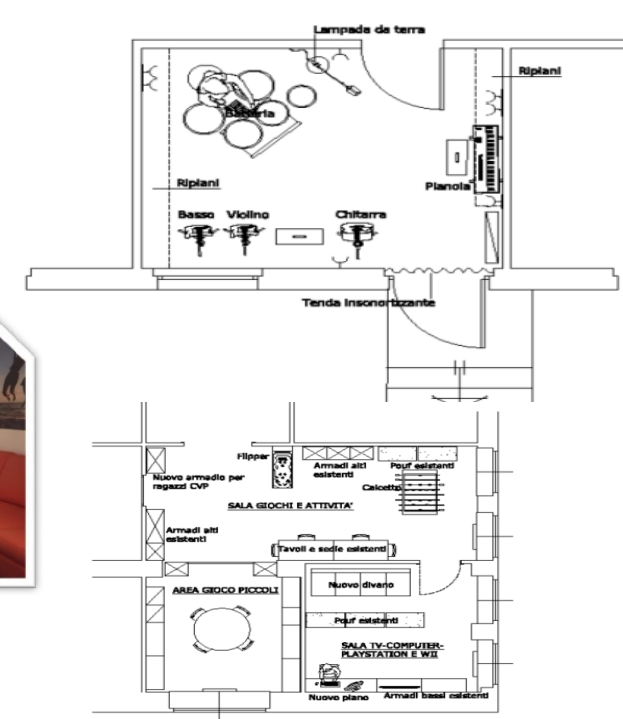
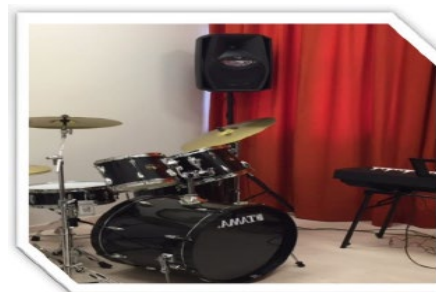
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GdL in
Italia

Easy Room

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Europa





GdL

Webinar con medici di famiglia/pediatri di base

GdL in
Italia

GdL in
Europa

WEB CONFERENCE

Le problematiche nella gestione degli adolescenti e giovani adulti con tumore

5 aprile 2022
h. 18.30 – 21.00

Programma

h. 18.30 – 18.45

Presentazione e apertura del corso (Franca Fagioli)

h. 18.45 – 19.00

Aspetti medici (Andrea Ferrari)

h. 19.00 – 19.15

Aspetti psicologici (Marina Bertolotti)

h. 19.15 – 20.15

Ritardo Diagnostico

Quando e come dobbiamo fare più in fretta (Paola Quarello)

Non è possibile che stia succedendo proprio a me (Giulia Zucchetti)

Non sono più un bambino e non ancora un adulto (Anna Bergadano)

Un altro prezzo da pagare: la pandemia (Anna Campello)

h. 20.15 – 20.45

Progetti locali (Daniele Bertin, Sebastian Asaftei, Simona Bellini, Domenico De Blasio)

h. 20.45 – 21.00

Discussione e chiusura del corso



REGIONE PUGLIA

Azienda Ospedaliero-Universitaria
Consorzio Policlinico di Bari
S.S. FORMAZIONE - POLO DIGITAL
Responsabile Dott. Riccardo De Luca



"Adolescenti e giovani adulti con tumore: conoscere di più per curare meglio"
CORSO WEBINAR SU PIATTAFORMA OFFERTA DALLA SOCIETÀ SCIENTIFICA AIEOP

6 giugno 2022

PROGRAMMA

17.00	17.15	Presentazione del corso, dei docenti e dei partecipanti Nicola Santoro – Teresa Perillo
17.15	17.20	Prima sessione – Moderatore: Maurizio Mascarin Adolescenti con tumore: aspetti medici Andrea Ferrari
17.20	17.40	Adolescenti con tumore: aspetti psicologici Chiara Rufigliano
17.40	18.00	DISCUSSIONE Seconda Sessione- Moderatori: Paola Quarello – Assunta Tornesello Del sintomo alla diagnosi. Principali sintomi, diagnosi differenziali e patologie tumorali in età adolescenziale Sintomi sentinella di tumori del sistema nervoso centrale Raffaella Messina
18.00	19.00	Il dolore osseo e le tumefazioni di tessuti molli Giuseppe Maria Milano Emocromo sballato Marco Spinelli Tumefazioni del collo: la punta di un iceberg Paola Muggeo
19.00	19.20	Terza Sessione - Moderatori: Valerio Cecinati – Saverio Ladogana SURVEI MMG e Pediatri Teresa Perillo
19.20	19.50	I progetti locali Teresa Perillo
19.50	20.00	Questionario on line



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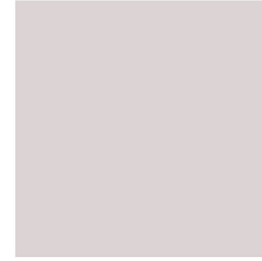
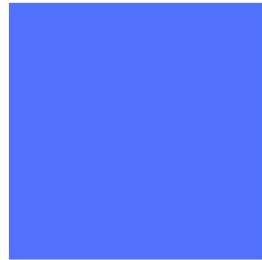
**A I O M
A I E O P**

INSIEME
PER ADOLESCENTI
E GIOVANI ADULTI
CON TUMORE



**A I O M
A I E O P**

INSIEME
PER ADOLESCENTI
E GIOVANI ADULTI
CON TUMORE



**A I O M
A I E O P**

INSIEME
PER ADOLESCENTI
E GIOVANI ADULTI
CON TUMORE






- Fedro Peccatori, Milano
(coordinatore)
- Angela Toss, Modena
- Giuseppe Banna, Torino
- Matteo Lambertini, Genova
- Lorena Incorvaia, Palermo



- Andrea Ferrari, Milano
(coordinatore)
- Paola Quarello, Torino
- Giuseppe Milano, Roma
- Maurizio Mascarini, Aviano
- Marta Canesi, Monza



Italian pediatric and adult oncology communities join forces for a national project dedicated to adolescents and young adults with cancer

Andrea Ferrari¹ , Paola Quarello²,
Maurizio Mascarini³, Giuseppe Luigi Banna⁴,
Angela Toss⁵, Giovanna Sironi¹ , Marco Zecca⁶,
Saverio Cinieri⁷ and Fedro Alessandro Peccatori⁸ 

Gennaio 2024
Ampliamento del gruppo

- Marco Maruzzo in sostituzione di Giuseppe Banna
- creazione “gruppo allargato” (oltre ai 10 membri formalmente riconosciuti):
 - 6 nuovi membri, 3 AIEOP (gli altri 3 membri del GdL AIEOP, Tornosello, Perillo, Spinelli), 3 AIOM (Indini, Baldi, Puccini)
 - gruppo psicologi: Giulia Zucchetti, Francesca Bomben, Elena Pagani Bagliacca e Elisabetta Razzaboni



XLVI Congresso Nazionale AIEOP

VIRTUAL 3-8 ottobre 2021

3 Ottobre 2021

AIEOP INCONTRA FIAGOP SALA VIRTUALE N.1

15:30-17:00

AIEOP, AIOM E FIAGOP: INSIEME PER ADOLESCENTI E GIOVANI ADULTI CON TUMORE

Moderatori: S. Cinieri, A. Ricci, M. Zecca

- Perché gli adolescenti e i giovani adulti con tumore sono pazienti speciali - *A. Ferrari*
- Il giovane con tumore: gli aspetti genetici - *P. Quarello, A. Toss*
- Il ruolo dell'associazione - *A. Ricci*
- Tavola Rotonda - *S. Cinieri, M. Zecca*

APPUNTAMENTI AIOM I MERCOLEDÌ DELL'ONCOLOGIA

"Né adulti, né bambini"

Intergruppo AIOM/AIEOP adolescenti e giovani adulti con cancro

Webinar

2 Marzo 2022
h. 17.00 - 18.15

PROGRAMMA

17.00 - 17.05

Presentazione del webinar
Saverio Cinieri, Francesco Perrone

Moderano: Andrea Ferrari, Fedro Peccatori

17.05 - 17.20

Overview generale su adolescenti e giovani adulti con cancro
Maurizio Mascarin

17.20 - 17.35

L'accesso alle cure e ai protocolli clinici
Paola Quarello

17.35 - 17.50

Gli aspetti psicosociali
Carlo A. Clerici

17.50 - 18.05

La genetica
Angela Toss

18.05 - 18.15

Q&A
Andrea Ferrari, Fedro Peccatori

XXV
CONGRESSO
NAZIONALE

Aiom

ROME
MARRIOTT
PARK
HOTEL

10.11.12
NOVEMBRE
2023
ROMA

8.00 - 9.00
INCONTRO CON L'ESPERTO
AFFETTIVITA' E SESSUALITA' NEI PAZIENTI ADOLESCENTI
E GIOVANI ADULTI
Moderatori: M. Mascarin (Aviano, PN), A. Toss (Modena)

8.05 Relatore
P. Quarello (Torino)

8.35 Discussione

XLVIII
CONGRESSO NAZIONALE
AIEOP

Bologna
2-4 Ottobre 2023
Hotel Savoia Regency




Sessione congiunta medici infermieri AIEOP **Sex, love and rock 'n roll** **Moderatori: M. Amicucci, A. Ferrari, A. Prete**

- 14:45-15:00 **Introduzione**
F. A. Peccatori
- 15:00-15:15 **Sesso**
P. Quarello
- 15:15-15:30 **Amore**
F. Bomben
- 15:30-15:45 **Rock 'n roll**
D. Greco



**Convegno Menarini
Milano, gennaio-febbraio 2025
Titolo: “C’è tempo...per la cura”
(patient involvement)**

Get up, stand up: Alongside adolescents and young adults with cancer for their right to be forgotten


Paola Quarello^{1,2}, Angela Toss³, Maurizio Mascarin⁴,
Giuseppe Luigi Banna⁵, Marta Canesi⁶, Giuseppe Maria Milano⁷,
Lorena Incorvaia⁸, Matteo Lambertini^{9,10}, Monica Trenziani¹¹,
Carlo Alfredo Clerici^{11,12}, Giulio Enea Vigevani¹³,
Giordano Domenico Beretta¹⁴, Arcangelo Prete¹⁵,
Saverio Cinieri¹⁶, Fedro Alessandro Peccatori¹⁷,
and Andrea Ferrari¹¹

Current Oncology Reports (2022) 24:843–860
<https://doi.org/10.1007/s11912-022-01213-3>

PEDIATRIC ONCOLOGY (KL DAVIS, SECTION EDITOR)



Cancer Predisposition Genes in Adolescents and Young Adults (AYAs): a Review Paper from the Italian AYA Working Group

Angela Toss^{1,2} · Paola Quarello^{3,4} · Maurizio Mascarin⁵ · Giuseppe Luigi Banna⁶ · Marco Zecca⁷ · Saverio Cinieri⁸ ·
Fedro Alessandro Peccatori⁹ · Andrea Ferrari¹⁰

Healthcare Professional Communication on Sexual Health: A Report from the Italian Working Group on Adolescents and Young Adults with Cancer

Paola Quarello^{1,2,3}, Angela Toss^{3,4,5}, Paola Berchialla⁵, Maurizio Mascarin⁶,
Matteo Lambertini^{7,8}, Marta Canesi⁹, Giuseppe Maria Milano¹⁰, Lorena Incorvaia¹¹,
Giuseppe Luigi Banna¹², Fedro Peccatori^{13,14}, Andrea Ferrari^{14,15}

The Oncologist, 2023, 28, e884–e890
<https://doi.org/10.1093/oncolo/oyad175>
Advance access publication 22 June 2023
Original Article



- Progetto Sessualità
 - survey operatori sanitari
 - survey pazienti
 - linee guida comunicazione

- Progetto Diritto all'Oblio

- Risk factors behind the increase of early onset cancer (EOC) in Italian adolescents and young adults (AYA)

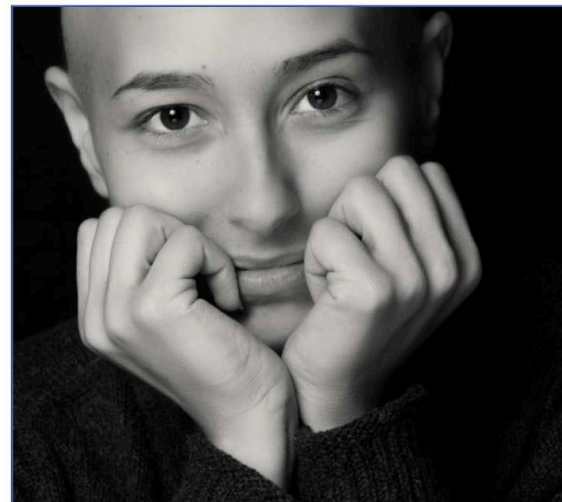
- Inclusione di AYA negli studi registrativi per farmaci - focus su dati italiani (EMA)

- Creazione centri AYA in AIOM





Andrea Ferrari & Fedro Peccatori
A cura di Edoardo Rosati



Nella Terra di Mezzo

**Insieme per gli adolescenti e
giovani adulti con tumore**





GdL

GdL in
Italia

GdL in
Europa

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- Owen Smith (Dublin, Ireland) – chair
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- Dan Stark (Leeds, UK)
- Valerie Laurence (Paris, France)
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- Maria Otth (Aarau, Switzerland)
- Paola Quarello (Turin, Italy)
- Paula Perez (Barcelona, Spain)
- Morgane Cleirec (Nantes, France)



European Parliament

Special Committee on Beating Cancer

PUBLIC HEARING

“From lab to life: transforming childhood, adolescent and rare cancer care”

Panel 2: Rights and needs of rare cancer and paediatric cancer patients, survivors, parents and caregivers

Tuesday, 23 February 2021

Putting Adolescents and Young Adults (AYA) under Spotlight

andrea.ferrari@istitutotumori.mi.it

Pediatric Oncology Unit - Youth Project - Fondazione IRCCS Istituto Nazionale Tumori of Milan

Chair Italian AIEOP Working Group on Adolescents
Chair SIOPE AYA Committee
Co-chair ESMO-SIOPE AYA Working Group

SIOP-E / ESMO AYA Working Group

initially founded for mainly educational purposes



- Andrea Ferrari (Chair), Italy (SIOPE)
- Emmanouil Saloustros (Chair) Greece (ESMO)
- Katrin Scheinemann, Switzerland (SIOPE)
- Daniel Stark, UK (SIOPE)
- Nathalie Gaspar, France (SIOPE)
- Matteo Lambertini, Italy (ESMO)
- Angela Toss, Italy (ESMO)
- Ivana Bozovic-Spasojevic, Serbia (ESMO)



REVIEW

Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE)

A. Ferrari^{1,2,11}, D. Stark^{2,11}, F. A. Peccatori³, L. Fern⁴, V. Laurence⁵, N. Gaspar⁶, I. Bozovic-Spasojevic⁷, O. Smith⁸, J. De Munter⁹, K. Derwich¹⁰, L. Hjorth¹¹, W. T. A. van der Graaf¹², L. Soanes¹³, S. Jezdic¹⁴, A. Blondeel¹⁵, S. Bielack¹⁶, J.-Y. Douillard¹⁴, G. Mountzios¹⁷ & E. Saloustros¹⁸

¹Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale Tumori, Milan, Italy; ²Leeds Institute of Medical Research, School of Medicine University of Leeds, Leeds, UK; ³Gynecologic Oncology Department, European Institute of Oncology IRCCS, Milan, Italy; ⁴Department of Oncology, University College London Hospitals NHS Foundation Trust, London, UK; ⁵Medical Oncology Department and SIREDO Oncology Center (Care, Innovation and Research for Children and AYA with Cancer), Institut Curie, Paris; ⁶Department of Oncology for Child and Adolescent, Gustave Roussy Cancer Campus, Villejuif, France; ⁷Medical Oncology Department, Institute for Oncology and Radiology of Serbia, Belgrade, Republic of Serbia; ⁸National Children's Cancer Service, Children's Health Ireland at Crumlin and Systems Biology Ireland, University College Dublin, Dublin, Ireland; ⁹University Hospital Ghent Cancer Center, UZ Gent, Ghent, Belgium; ¹⁰Department of Pediatric Oncology, Hematology and Transplantation, Poznan University of Medical Sciences, Poznan, Poland; ¹¹Lund University, Skane University Hospital, Department of Clinical Sciences Lund, Pediatrics, Lund, Sweden; ¹²Department of Medical Oncology, The Netherlands Cancer Institute, Amsterdam, The Netherlands; ¹³Teenage Cancer Trust, London, UK; ¹⁴Scientific and Medical Division, European Society for Medical Oncology (ESMO), Lugano, Switzerland; ¹⁵Department of Scientific Programme Coordination, European Society for Paediatric Oncology (SIOPE), Brussels, Belgium; ¹⁶Zentrum für Kinder, Jugend und Frauenmedizin Pädiatrie 5, KlinikumStuttgart – Olga Hospital, Stuttgart, Germany; ¹⁷2nd Department of Medical Oncology and Clinical Trial Unit, Henry Dunant Hospital, Athens; ¹⁸Department of Oncology, University Hospital of Larissa, Larissa, Greece

Available online XXX

It is well recognised that adolescents and young adults (AYA) with cancer have inequitable access to oncology services that provide expert cancer care and consider their unique needs. Subsequently, survival gains in this patient population have improved only modestly compared with older adults and children with cancer. In 2015, the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) established the joint Cancer in AYA Working Group in order to increase awareness among adult and paediatric oncology communities, enhance knowledge on specific issues in AYA and ultimately improve the standard of care for AYA with cancer across Europe. This manuscript reflects the position of this working group regarding current AYA cancer care, the challenges to be addressed and possible solutions. Key challenges include the lack of specific biological understanding of AYA cancers, the lack of access to specialised centres with age-appropriate multidisciplinary care and the lack of available clinical trials with novel therapeutics. Key recommendations include diversifying interprofessional cooperation in AYA care and specific measures to improve trial accrual, including centralising care where that is the best means to achieve trial accrual. This defines a common vision that can lead to improved outcomes for AYA with cancer in Europe.

Key words: adolescents and young adults, cancer, clinical trials, education, interdisciplinary

INTRODUCTION

In recent years, the specific challenges related to the management of adolescents and young adults (AYA) with

cancer are increasingly well recognised.¹ These challenges include inequitable access to oncology services which provide expert cancer care and consider their unique needs as AYA. In addition, the complex psychological, social and financial impact of a cancer diagnosis during a period of rapid physiological, personal and psychological growth affects well-being in significant ways.² Consequently, survival gains have improved only modestly compared with adult and childhood cancers.³

The challenges of appropriate models of care for AYA with cancer have been appreciated by the scientific community⁴ and it is now well documented that traditional health care models do not meet the unique needs of AYA.^{5,6}

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ENTYAC - European Network for Teenagers and Young Adults with Cancer

as 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

- Dan Stark – chair
- Andrea Ferrari
- Ivana Bozovic
- Ashley Gamble
- Anna Castleton
- Anita Kienesberger
- Carina Schneider
- Johan De Munter
- Assia Konsoulova-Kirova
- Katie Rizvi

A European Network for Teenagers and Young Adults with Cancer

Ivana Bozovic-Spasojevic, MD, PhD,¹ Marie Balsat, MD,²
Anne Blondeel,³ Anna Castleton, MBBS, MRCP, FRCPATH, PhD,⁴ Johan De Munter, RN,⁵
Ashley S. Gamble,⁶ Anita Kienesberger, MA,⁷ Assia Andrianova Konsoulova-Kirova, MD, PhD,⁸
Katie Rizvi,⁹ Carina Schneider, MSc,^{10,11} Josefien Vermeersch,¹²
Andrea Ferrari, MD,^{13,*} and Daniel Stark, MB BChir, MA, PhD, FRCP^{14,*}

THE HUGE CHALLENGES of having cancer at a young age are well described. The challenges of providing cancer care services for this patient group are also increasingly described, although new challenges of increasing disease and new patterns of disease are also emerging.¹ Questions clearly remain about what we do to provide optimal care for this challenge, medical and psychosocial. Effective teamwork is critical.^{2,3} Providing specialized teams with a focus on this group, which brings together experts on cancer in younger children and older adults, is one approach, and brings measurable clinical benefits to patients treated in that setting.⁴ However, such models of care inevitably also have weaknesses, potentially including disjointed care and inequity of access.⁵

As care coordination challenges for patients with cancer continue to grow, as cancer treatment and care become more and more complex, the need to work both within a team and to coordinate across disciplines, organizations, and geographic boundaries increases.⁶ Wider networks and even inter-team working may be useful next steps to improve clinical outcomes, including cancer control and quality of life, reduce treatment-related medical errors and manage care costs.⁷ Some believe cancer care is moving inevitably beyond improving the teamwork processes within the teams directly involved, toward a network of interdependent teams, across specialities and geographies.⁸

Adolescent and young adult (AYA)-specific specialist care systems are especially complex and multiteam. They often

require engagement with pediatric and adult care models, covering oncological and hematological malignancies. They benefit from a particular set of engagements between patients, their families, and service providers.^{9,10} The specific challenges in coordinating professional stakeholder groups range from the clinical and biological (such as diagnosis and appropriate protocol selection^{11,12}) to the psychological and social domain where an even wider range of health care professional expertise is required.^{13–15} Many cancers seen are rare and, therefore, wide-enough information exchange is challenging. A lack of such wide inter-team working may be contributing to disappointing timescales between symptoms and cancer diagnosis and treatment, with associated poorer outcomes for many young patients.^{16–18} These challenges to networks are only going to become wider, according to current epidemiological trends, including interventions for healthy lifestyle in cancer survivors.^{19,20}

The provision of services to AYA remains very variable. A survey conducted in 2017 described the training and different practices of European health care providers in regard to AYA and the availability of specialized AYA services. This revealed important under-provision and inequity of specialized AYA cancer care across Europe, particularly evident in Eastern and South-Eastern Europe. Over two-thirds of respondents did not have access to specialized centers for AYA (67%), were not aware of research initiatives focusing on AYA with cancer (69%) and had no access to specialist services for managing the late effects of treatment (67%).

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⁹Youth Cancer Europe, Cluj-Napoca, Romania.

¹⁰CCI Europe, Vienna, Austria.

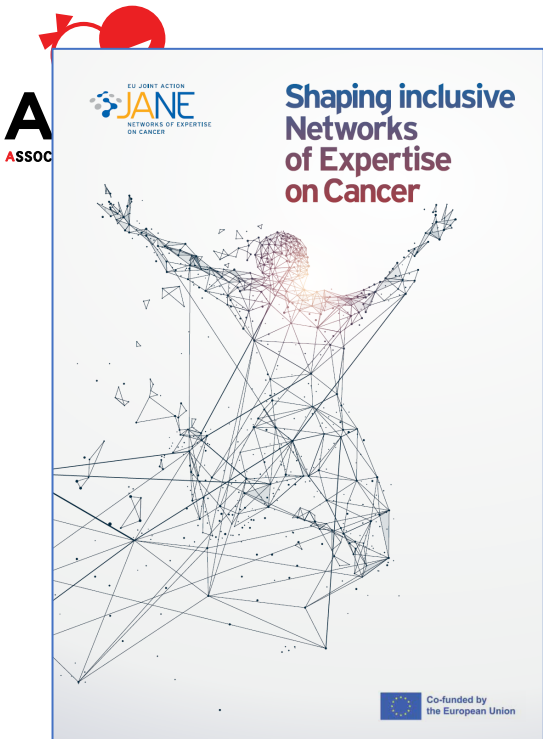
¹¹Medical University of Vienna, Vienna, Austria.

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¹⁴Leeds Institute of Medical Research, School of Medicine, University of Leeds, Leeds, United Kingdom.

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- coordinated by Fondazione IRCCS, Istituto Nazionale dei Tumori di Milano, Italy (P.Casali, A.Trama)
- **JANE 1** – Oct 2022-Oct 2024: 2-year program aiming at shaping seven new Networks of Expertise (NoEs) in the cancer field, with the ambition of paving the way for new NoEs able to function effectively
- **JANE 2** – Nov 2024 – Nov 2028: 4-year program
- The NoEs will be the same WPs of JANE 1

WP11 - NoE on Adolescents and Young Adults with Cancer (PI Andrea Ferrari)

High Contribution: Milano, Torino
Low Contribution: Aviano
Observer: Monza

