

In rare diseases, everything starts with a patient

- ❖ Organizations such as **EURORDIS** and **Orphanet** consistently state that: rare disease knowledge often begins with **individual case reports**
- ❖ Patients and families are **drivers of discovery**
- ❖ Registries, biobanks, and research questions originate from single patients

Towards Patient-Centered Healthcare: From patient involvement to the involvement of patient associations and citizens.

CHALLENGES

Investment in
technologies

Cultural
resistance

Data collection

Data
interpretation

Training of
healthcare
professionals



BENEFITS

Participatory
Medicine

Sustainability

FUTURE PERSPECTIVES

A more equitable
healthcare
system

Greater
efficiency

Increased focus
on the patient

Excerpt from the Final Project "PREMs, PROMs and Participatory Healthcare: from patient involvement to the involvement of patient associations and citizens."
Donatella Capone, Lara Consani, Barbara Nadine De Gol, Marta Nicolato, Elena Schievano, Master's Degree in Patient Advocacy Management, Cattolica University, Rome.

From Experience to Action: Why NAnA Was Born

- Transform pain into knowledge
- Patient support
- Research support
- Training & mediation
- Networking



www.nanaets.org

nana@nanaets.org

NAnA was born to fill systemic gaps, not to replace Institutions

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NAC, THE NAnA ALUMNI COMMUNITY

Prof. Stefano Casola, IFOM Milan,
Scientific Coordinator



Gabriele Loiudice
2020 Phd scholarship
for a young postdoctoral
researcher, providing
funding to the Regina
Elena Institute in Rome.



Carmelo Gurnari

NAnA-SIES Award 2024

2024: NAnA SIES (Italian
Society of Experimental
Hematology) Award for
young researchers for a
work published in the
last 3 years in an indexed
international journal, as
first or last author, on the
topic of myeloid
neoplasms.



**Maria Rosaria
Pascale**

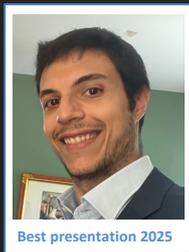
1 year Phd fellowship 2022

2022: Phd scholarship
for a young female
researcher through
funding to the
University of Rome Tor
Vergata.

Since 2016:

NAnA-SIBBM Award for the best scientific presentation on cancer by a young scientist at the annual SIBBM workshop.

Winners are selected by a special committee established each year by the SIBBM Board.



Established in 2021

Francesca Martini Award for an Experimental Graduate Thesis in Oncohematology

Evaluation Committee

Cristina Mecucci, University of Perugia, President

Andrea Biondi, University of Milan Bicocca and Fondazione Tettamanti

Stefano Casola, IFOM, Milan

Francesco Mannelli, University of Florence

Tiziana Ottone, University of Rome Tor Vergata

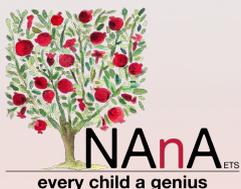
Vincitrice 2023
Simone Pirogoli, vincitrice del Premio Francesca Martini per una tesi di Laurea di tipo sperimentale in Oncematologia dell'importo di €5.000.
"Qualità di un potenziale nuovo target terapeutico per la Leucemia Linfoblastica Acuta (Linfoma MLL-Hemoglobin)"
[SCOPRI DI PIÙ](#)

The Winner in 2024 is **Alessia Labate**, University of Turin, with her thesis on "Diacylglycerol kinase alpha promotes ubiquitination and cell surface downregulation of chimeric antigen receptor"

Vincitore 2022
Matteo di Giovanni, vincitore del Premio Francesca Martini per una Tesi di Laurea di tipo Sperimentale in Oncematologia dell'importo di €5.000.
"La caratterizzazione del regime della Leucemia Linfoblastica Acuta pediatrica rivela meccanismi di evoluzione tumorale"
[SCOPRI DI PIÙ](#)

The Winner in 2025 is **Mara Algeri**, University of Turin, with her thesis on "Dual bioluminescent imaging in humanized bone marrow organoid models to study CAR-CIK cell trafficking and anti-leukemic activity in Acute Myeloid Leukemia."

Vincitrice 2021
Giorgia Silvestri, vincitrice del Premio Francesca Martini per una Tesi di Laurea di tipo sperimentale in Oncematologia dell'importo di €3.000.
"Investigazione del pathway del TGF- β in pazienti affetti da sindrome mielodisplastica con mutazione del gene EP300"
[SCOPRI DI PIÙ](#)



XIX Congresso Nazionale
Società Italiana di Ematologia Sperimentale



Premio NANA-SIES 2026

Dott.ssa Martina Sarchi

Università di Pavia, Dipartimento di Medicina Molecolare

Per l'articolo scientifico:

*“Mis-splicing of Mitotic Regulators Sensitizes SF3B1-Mutated Human
HSCs to CHK1 Inhibition”*

Blood Cancer Discov (2024) 5 (5): 353–370.

Firenze, 5 Marzo 2026

Presidente NANA ETS