

**Emoglobinuria parossistica notturna:
fra diagnosi, ottimizzazione della terapia e modelli assistenziali.**

17 aprile 2026.

Sala Convegni Ospedale San Bassiano – Bassano del Grappa

Responsabile scientifico: Eros Di Bona

Evento Residenziale per 70 discenti (Medico Chirurgo; Medico di Medicina Generale)

Programma Scientifico

17 aprile:

Incontro riservato ai Medici ospedalieri e di Medicina Generale che hanno in cura pazienti con EPN

ore 14: registrazione dei Partecipanti

ore 14.30: saluti da parte delle Autorità e presentazione delle giornate

ore 15.00: Tavola Rotonda: *malattie rare, modelli organizzativi per un'assistenza ottimale*

ore 16.00: *EPN fra clonalità e autoimmunità*

Lucio Luzzatto

ore 16.30: *il complemento*

Rosario Notaro

ore 17.00: *aspetti clinici dell'EPN*

Wilma Barcellini

ore 17.30: *terapia anti complementare: oltre l'inibizione del C5?*

Simona Sica

ore 18.00: *EPN abbiamo scoperto tutto? Problematiche cliniche e terapeutiche ancora aperte*

Antonio Risitano

ore 18.30: chiusura della giornata

Razionale Scientifico

L'emoglobinuria parossistica notturna (EPN) è rara malattia genetica, acquisita e non ereditaria, clonale, non neoplastica. Nel Veneto, con una popolazione stimata nel 2023 in 4.852.216 abitanti, dovrebbero esserci circa 9 nuovi casi/anno e una prevalenza di 87 casi di EPN. A fronte di una relativa facilità tecnica nel porre la diagnosi, esiste una discrepanza fra i casi attesi e quelli osservati. Questo può dipendere dall'elevata eterogeneità clinica, difficoltà nel riconoscimento e quindi nella diagnosi.

Dal 2007, con l'introduzione di eculizumab, anticorpo che inibisce il complemento, sono enormemente cambiate la possibilità di sopravvivenza ed è migliorata la qualità di vita. Negli ultimi anni sono stati sperimentati e sono arrivati alla registrazione ben altri cinque farmaci con diversi target, capaci di migliorare anche chi non risponde completamente ad eculizumab.

Questa offerta terapeutica pone a chi si occupa di EPN la necessità di definire un percorso di terapia rivolto al singolo paziente. Inoltre diventa necessario un confronto diretto con gli Enti preposti alla regolamentazione della spesa sanitaria, visto l'alto costo di queste terapie.

Recentemente la Regione Veneto ha approvato un documento contenente le linee guida di indirizzo diagnostico terapeutico per l'EPN, nell'ambito delle Rete Ematologica Veneta (REV). Questo è solo l'inizio di un dialogo aperto fra tutte le figure coinvolte nella cura del paziente con EPN, per poter assicurare diagnosi puntuale, assegnazione della migliore terapia, monitoraggio adeguato, accesso alle urgenze e valutazione nel contesto di una rete che concretamente coinvolga centri di somministrazione con specialisti dedicate alla conoscenza dell'EPN.

ACRONIMI

EPN = emoglobinuria parossistica notturna

Complemento C5 = proteina sierica che aiuta a eliminare agenti patogeni



Curriculum Vitae Europass

Curriculum Formativo e Professionale della Dott.ssa Silvia Adami

Ai sensi e per gli effetti degli artt. 46 e 47 del DPR n. 445/2000 la sottoscritta dichiara quanto segue:

INFORMAZIONI PERSONALI		
Nome		SILVIA ADAMI
Residenza		Verona
E-mail		silvia.adami@ymail.com
Nazionalità		Italiana
Anno di nascita		1977
ESPERIENZA LAVORATIVA		
Dal 01/12/2008 a tutt'oggi.		Dirigente Farmacista c/o Azienda ULSS n. 9 Scaligera.
Dal 01/01/2024 a tutt'oggi.		Distacco presso Direzione Farmaceutico Protesica Dispositivi medici – Area Sanità e Sociale – Regione del Veneto.
Principali mansioni, responsabilità e competenze:		Referente delle seguenti materie: Carenze farmaci, logistica dei farmaci acquisiti centralmente nelle emergenze e gestione delle importazioni di farmaci in ospedale e sul territorio; Accesso precoce ai farmaci (Fondo 5%, L.648/96, CNN); Area delle malattie rare -Centro regionale Malattie Rare; Commissione regionale GH; Gruppo di lavoro per la valutazione e il monitoraggio dei farmaci biologici per l'area reumatologica, l'area dermatologica e l'area gastroenterologica, istituito con Decreto del Direttore della Direzione Farmaceutico, Protesica, Dispositivi Medici n. 4 del 22 febbraio 2024; Piattaforma Regionale Cannabis, Piattaforma Regionale Usi Off-Label, Registro malattie rare e Piattaforma informatizzata regionale per l'informazione medico-scientifica; Stupefacenti e Cannabis – GdL Cannabis; Monitoraggio attività delle Commissioni Terapeutiche Aziendali/Sovraziendali; Galenica Clinica; Informazione medico scientifica; Recupero farmaci; Definizione Standard FO/SFT; Percorsi farmaceutici ospedalieri compreso il Coordinamento dei Gruppi di lavoro; Trasmissione di tutti gli aggiornamenti nazionali relativi all'Area dei prodotti medicinali, in accordo con i referenti delle altre aree; Adozione atti da CTRF – Ospedale (esclusi autorizzazione Centri).
Dal 15/02/2021 al 31/12/2023		Dirigente Farmacista a tempo indeterminato e a tempo pieno c/o UOC Assistenza Farmaceutica Territoriale.
Principali mansioni, responsabilità e competenze		Gestione dei microinfusori e dei sistemi per il monitoraggio continuo della glicemia (sistemi CGM) real-time non associati al microinfusore di tutti i pazienti della Azienda ULSS n. 9 Scaligera; Referente Aziendale per le carenze dei farmaci territoriali; Referente Aziendale per la Piattaforma Servizi Farmaceutici (PSF) regionale; Referente Area Territoriale per la Piattaforma Registri AIFA – aggiornamento anagrafiche come da nota del Direttore Sanitario Aulss9, Prot. N. 21534 del 01/02/2023; Componente della Commissione Terapeutica Sovraziendale (C.T.S.) come da Deliberazione n. 944 del 30 settembre 2022 (Prot. N. 62916 del 18/10/2022); Componente della "Commissione per la valutazione degli usi off-label di medicinali e trattamenti indispensabili e insostituibili, riconducibili ai livelli essenziali di assistenza (LEA)" come da DDG n. 737 del 26/07/2023 e n. 1387 del 27/12/2023; Partecipazione a gruppi di lavoro finalizzati alla stesura di documenti tecnici, con particolare riferimento al "PDTA aziendale per la gestione integrata della persona adulta con Diabete di tipo 2", trasmesso con nota Prot. N. 92282 del 11 maggio 2023; Componente supplente della "Commissione ispettiva di vigilanza e controllo sulle farmacie e magazzini prevista dall'art. 16 della L.R. n. 78/1980 e s.m.i." come da Deliberazione del Direttore Generale n.808 del 09/08/2022;

	Componente del Gruppo Tecnico incaricato di redigere le caratteristiche indispensabili e preferenziali dei prodotti rientranti nella seguente gara centralizzata "Gara regionale per sistemi diagnostici per la rilevazione della glicemia in ambito ospedaliero 2^a edizione" (Nota UOC CRAV del 17 marzo 2023); Gestione richieste ADI distretto 1 Verona città (sede Capitel) e Distribuzione Diretta; Attività di informazione rivolta a pazienti, MMG e PLS, specialisti, infermieri, farmacisti; Tutoraggio nelle discipline/tematiche specificamente rivolte a Farmacisti in formazione specialistica in Farmacia Ospedaliera; Gestione delle richieste provenienti dai Centri di Servizi del Distretto 1 Verona città (valutazione e validazione delle richieste per singolo paziente, attività di consulenza, ispezioni) dal 16/02/2021 al 01/03/2023.
Dal 05.11.2018 al 14.02.2021	Dirigente Farmacista a tempo indeterminato e a tempo pieno c/o UOC Farmacia Ospedaliera – Ospedale di San Bonifacio
Principali mansioni, responsabilità e competenze	Gestione dei microinfusori e dei sistemi per il monitoraggio continuo della glicemia (sistemi CGM) real-time non associati al microinfusore dei Distretti 1-2-3; Gestione richieste ADI e Case di riposo dei distretti n. 1 Verona città e n. 2 Est veronese; Validazione delle richieste a scorta e per singolo paziente delle UU.OO. degli Ospedali di San Bonifacio e Marzana; gestione richieste urgenti dei reparti; Distribuzione Stupefacenti; Distribuzione Diretta; Partecipazione alle diverse fasi di acquisizione dei beni farmaceutici e dispositivi medici; definizione dei fabbisogni; promozione ed attuazione dei criteri di efficacia, appropriatezza ed efficienza, economica; collaborazione con Provveditorato e Controllo di Gestione; Referente Aziendale per la Piattaforma Servizi Farmaceutici (PSF) regionale.
Dal 01.01.2013 al 31.12.2017	Distacco presso Direzione Farmaceutico Protesica Dispositivi medici - Regione del Veneto.
Principali mansioni, responsabilità e competenze	Referente delle seguenti materie: Galenica clinica e oncologica (dal 01.01.2013 al 31.12.2017); Rischio clinico (dal 01.01.2013 al 31.12.2017); Epatite C (dal 01.02.2014 al 31.12.2017); HIV (dal 30.07.2015 al 31.12.2017); Cannabinoidi per finalità terapeutiche (dal 01.01.2016 al 31.12.2017); Antidoti (dal 01.02.2014 al 31.12.2017); Segreteria del "Gruppo di Lavoro sui Farmaci Oncologici innovativi" - Supporto metodologico alla predisposizione delle Raccomandazioni n. 1-20 approvate con DDR; Segreteria del "Gruppo di Lavoro sui Farmaci Oncoematologici innovativi" - Supporto metodologico alla predisposizione delle Raccomandazioni n. 1-5 approvate con DDR; Responsabile della sezione Valutazione Farmaci del Coordinamento Regionale Unico sul Farmaco (CRUF) (dal 01.02.2014 al 31.12.2015); Segreteria Commissione Tecnica Regionale Farmaci (dal 01.01.2013 al 31.05.2013); Assistenza Protesica (dal 01.02.2014 al 31.12.2015); Registri AIFA (dal 01.01.2013 al 31.05.2013); Sperimentazione clinica (dal 01.01.2013 al 31.05.2013).
Dal 01.12.2008 al 31.12.2012	Dirigente Farmacista presso UOC Farmacia Ospedaliera - Ospedale di Legnago
Principali mansioni, responsabilità e competenze	Validazione delle richieste di farmaci, dietetici, dispositivi medici a scorta e per singolo paziente delle UU.OO, case di riposo, assistenza domiciliare; distribuzione stupefacenti, distribuzione diretta; costante lavoro di front office con pazienti, medici, specialisti, farmacisti e altri operatori sanitari; Verifiche ispettive sulla corretta gestione e utilizzo dei farmaci e dispositivi medici all'interno delle UU.OO. e delle case di riposo; Segreteria scientifica del Nucleo per l'Appropriatezza di Impiego dei Farmaci.
Dal 09.12.2003 al 30.11.2008	Borsista presso Unità di Valutazione Efficacia del Farmaco (38 ore settimanali)
Principali mansioni, responsabilità e competenze	Stesura di report di Health Technology Assessment per le molecole oggetto di valutazione della Commissione Tecnica Regionale Farmaci; Predisposizione e aggiornamento Prontuario Terapeutico Regionale Ospedaliero (PTORV) e delle case di riposo; Partecipazione a progetti di ricerca in farmacoepidemiologia coordinati dall'UVEF. Componente del Comitato di redazione del "Bollettino di informazione UVEF" - Centro di Riferimento Regionale sul Farmaco – Unità di Valutazione dell'Efficacia del Farmaco da Gennaio 2005 a Novembre 2008.

ISTRUZIONE E FORMAZIONE		
24.09.2003		Università degli Studi di Padova
Qualifica conseguita		Laurea in Farmacia con Votazione di 110/110 e Lode. Tesi Sperimentale dal titolo: "Impatto del fattore sesso sulla segnalazione spontanea delle reazioni avverse da farmaci: analisi dei dati della segnalazione spontanea in Emilia-Romagna, Lombardia e Veneto e Provincia Autonoma di Trento."
Il sessione 2003		Università degli Studi di Padova
Qualifica conseguita		Abilitazione alla professione
19.07.2006		Università degli Studi di Padova
Qualifica conseguita		Specializzazione in Farmacia Ospedaliera con voti 70/70 e Lode. Tesi Sperimentale dal titolo: "Impatto di un centro di informazione sul farmaco sulle scelte terapeutiche di operatori sanitari in ambito ospedaliero e specialistico".
Anno accademico 2007-2008		Università degli Studi di Firenze
Qualifica conseguita		Diploma di Corso di Perfezionamento Post-Laurea in "Farmacoeconomia e Socioeconomia".
15.06.2012		Università degli Studi di Camerino
Qualifica conseguita		Master Universitario di II livello: Manager di Dipartimenti Farmaceutici con voti 110/110 e Lode con Tesi dal titolo: "Analisi critica della metodologia valutativa per l'inserimento di nuovi farmaci nel Prontuario Terapeutico Regionale".
Anno accademico 2013-2014		Università Cattolica di Roma
Qualifica conseguita		Diploma di Corso di Perfezionamento Post-Laurea in "Valutazione delle tecnologie e degli interventi in Sanità".
Referente nazionale SIFO per l'ECM e Coordinatore del Gruppo di lavoro FAD (quadriennio 2020-2024); Consigliere Nazionale del Consiglio Direttivo SIFO (quadriennio 2012-2016); Coordinatore del Comitato Scientifico per la Formazione SIFO (quadriennio 2012-2016); Coordinatore del Gruppo Giovani SIFO (quadriennio 2008-2012); Componente del Comitato Scientifico Unico Ricerca e Formazione SIFO (quadriennio 2016-2020 e del Comitato Scientifico SIFO (quadriennio 2008-2012); Componente del Comitato Editoriale delle Riviste "Giornale Italiano di Farmacia Clinica" e "Bollettino SIFO" (quadriennio 2012-2016); Collaboratore dell'Area Scientifico culturale SIFO "Oncologia" (quadriennio 2016-2020) e "Rischio clinico" (quadriennio 2008-2012, 2012-2016 e 2016-2020); Collaboratore del Laboratorio SIFO di Farmacoeconomia diretto dal Dr Andrea Messori (quadriennio 2008-2012). n. 88 partecipazioni a Congressi/Convegni/Corsi in qualità di relatore o moderatore; n. 63 partecipazioni a Congressi/Corsi/Convegni in qualità di responsabile scientifico o componente del Comitato Scientifico/Organizzatore; n. 34 pubblicazioni di articoli scientifici su riviste nazionali e internazionali; n. 62 pubblicazioni come abstract presentati a Congressi; partecipazione alla stesura di n. 12 testi scientifici.		

Verona, 25/05/2024

Silvia Adami 

Autorizzo il trattamento dei dati personali presenti nel CV ai sensi del D.Lgs. 2018/101 e del GDPR (Regolamento UE 2016/679).

Verona, 25/05/2024

Silvia Adami 

PERSONAL INFORMATION

Wilma Barcellini



Work: Padiglione Granelli, Via Francesco Sforza 35, 20122 Milano
 House: Viale Bligny 43, 2136 Milano
 Work: 0255033256, 0255033426
 House: 0258316231 Personal mobile: 3382953704
 wilma.barcellini@policlinico.mi.it

Sex Female | Date of birth 01/04/1956 | Nationality Italian
 FC BRCWLM56D41F205J

PRESENT JOB POSITION

- 2025-pres Honorary scientific collaborator at Hematology Unit, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico of Milan 2017-pres
- Qualified Associate Professor in Blood diseases, Oncology and Rheumatology (Bando DD 1532/2016, 06D3, fascia II)

WORK EXPERIENCE

- 19.12.07 –31.12.2024 Director of Pathophysiology of Anemias Unit, Hematology Unit, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico of Milan
- 1.11.22- 31.12.2024 Deputy Director of Hematology Unit, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico of Milan
- 1.5.97 -18.12.07 Medical assistant, Department of Hematology, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico of Milan
- 1.3.91- 30.4.97 Medical assistant, Department of Internal Medicine, Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico of Milan
- 1992, Visiting scientist at the Laboratory of Immunology, directed by . A. Dalglish, Division of Oncology, St George's Hospital, University of London, UK.
- 1990-1991 Research scholarship holder by Istituto Superiore di Sanità, aimed to study AIDS in Italy
- 1988-1990 Research scholarship holder (two years) by Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico of Milan at the Medical Clinic I
- 1986-1988 Contract Research holder (two years) by Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico of Milan at the Medical Clinic II
- 1988, Visiting scientist at the Laboratory of Immunology, directed by prof. R.H. Zubler, Department of Medicine, University Hospital Geneva, Switzerland
- 1987 Specialization in Rheumatology, University of Milan (honor)
- 1983 Specialization in Clinical Immunology, University of Milan (honor)
- 1981-1986 Resident physician at the Medical Clinic IV, and Medical Clinic II USM
- 1980 Degree in Medicine (honor), University of Milano
- 1/4/81-30/9/81 Practical training at the Hospital Niguarda Ca' Granda (Medicine).
- 1974-1980 Medical school, University of Milano
- 1974 High School Diploma in Sciences (60/60).

Mother tongue(s) italian

Other language(s)

	UNDERSTANDING		SPEAKING		WRITING
	Listening	Reading	Spoken interaction	Spoken production	
English	B	C	B	B	C

Levels: A1/2: Basic user - B1/2: Independent user - C1/2 Proficient user
 Common European Framework of Reference for Languages

(1993-2014)

Responsibile of 30 Research Projects of Ospedale Maggiore Policlinico di Milano, Istituto Superiore di Sanità, Ricerca Finalizzata Ministero Sanità .

Principal Investigator of 28 Study Protocols

Invited speaker at more than 100 National and International Congresses

Author of 327 full papers in journals indexed on Science Citation Index (<https://www.ncbi.nlm.nih.gov/pubmed/?term=barcellini+w>).
Scopus H Index: 50.

Co-Author of 20 Books/Chapters

Author of more than 250 abstracts published on Journals indexed by Science Citation Index

Participation in more than 100 National and International Meetings with more than 300 communications (poster / oral).

Scientific Organization of 20 Meetings (ECM)

Honours and awards / Memberships

Winner of Young Research Award Milanomedicina 1985.
Winner Italian Roussel Scientific Institute of Research 1988/1989
Member of the Board WP GIMEMA Anemia and Thrombocytopenia
Member of the Board WP GIMEMA Rare non neoplastic diseases
Vice President of the Association STEM ONLUS until 2016
Member of the REL Comitee for Hemostasis thrombosis and thrombocytopenia
Member of the REL Comitee for Anemias
Member of the ERN, European Reference Networks
Referee of several international scientific journals including New England Journal of Medicine, Lancet Haematology, Blood, Haematologica, British Journal of Haematology, American Journal of Haematology, European Journal of Internal Medicine, Blood Transfusion.
Member of the Editorial Advisory Board of American Journal of Hematology
Referee for Abstracts of the 19th and 25th Congress of the European Hematology Association
Correlator of degree and specialization thesis in Medicine and Biology

I declare to be qualified by education and experience to assume responsibility for the proper conduct of trial and to have knowledge and to comply with Good Clinical practice (GCP). Last GCP training performed on 28 Dec 2021

I authorize the processing of my personal data according to the Legislative Decree 30 June 2003, n. 196 " protection of personal data." And the Regulation (EU) 2016679 (General data Protection Regulation – GDPR)

- *Il sottoscritto è a conoscenza che, ai sensi dell'art. 76 del DPR 445/2000, le dichiarazioni mendaci, la falsità negli atti e l'uso di atti falsi sono puniti ai sensi del codice penale e delle leggi speciali. Inoltre, il sottoscritto, consapevole dei diritti relativi al capo III del Reg. UE 679/16 - GDPR, con la sottoscrizione del presente documento, presta esplicito ed inequivocabile consenso ex art. 7 Reg. UE 679/16, al trattamento dei propri dati personali ai fini per cui il presente CV viene chiesto.*

Wilma Barcellini

Milan, 8 Jan 2026



CARRETTA GIOVANNI

Data di nascita: 11/11/1970
Luogo di nascita: PADOVA (PD)

03/07/1996 - Albo provinciale di MEDICINA E CHIRURGIA (Ordine della Provincia di PADOVA) n. 0000008131	iscrizioni
Data conseguimento: 17/10/1995 Università: PADOVA	lauree
1996 / 1 - Medicina e Chirurgia (VERONA)	abilitazioni
09/01/2008 - IGIENE E MEDICINA PREVENTIVA (PADOVA)	specializzazioni
25/10/1999 - MALATTIE INFETTIVE (VERONA)	specializzazioni

Data aggiornamento: 12/03/2026

L'elenco dei medici e degli odontoiatri riportati in questo servizio è stato realizzato sui dati comunicati dagli Ordini Provinciali. È opportuno ricordare che ai sensi dell'art. 1 del DPR n. 221 del 5 aprile 1950 la competenza alla tenuta degli Albi dei Medici Chirurghi e degli Odontoiatri spetta ai singoli Ordini Provinciali. Si fa presente altresì che la data di iscrizione all'Ordine Provinciale è riferita alla situazione attuale e non alla data di la iscrizione.

CAZZARO ROMINA

Data di nascita: 26/01/1977
Luogo di nascita: VICENZA (VI)

19/07/2006 - Albo provinciale di MEDICINA E CHIRURGIA (Ordine della Provincia di VICENZA) n. 0000005327	iscrizioni
Data conseguimento: 26/03/2003 Università: PADOVA	lauree
2003 / 2 - Medicina e Chirurgia (PADOVA)	abilitazioni
27/05/1998 - IGIENE E MEDICINA PREVENTIVA (PADOVA)	specializzazioni

Data aggiornamento: 19/03/2026

L'elenco dei medici e degli odontoiatri riportati in questo servizio è stato realizzato sui dati comunicati dagli Ordini Provinciali. È opportuno ricordare che ai sensi dell'art. 1 del DPR n. 221 del 5 aprile 1950 la competenza alla tenuta degli Albi dei Medici Chirurghi e degli Odontoiatri spetta ai singoli Ordini Provinciali. Si fa presente altresì che la data di iscrizione all'Ordine Provinciale è riferita alla situazione attuale e non alla data di la iscrizione.



Curriculum Vitae Europass

Informazioni personali

Nome(i) / Cognome(i)	Eros Di Bona
Indirizzo(i)	viale Grappa, 51 - 36100, Vicenza, Italia
Telefono(i)	+39 3483429883
Fax	
E-mail	eros.dibona@aulss7.veneto.it
Cittadinanza	Italiana
Data di nascita	24 febbraio 1959
Sesso	Maschile
Codice Fiscale	DBNRSE59B24L840Z

Occupazione professionale

Dirigente Medico - ULSS 7 Pedemontana- Direttore UOC Oncoematologia

Esperienza professionale

Medico Ospedaliero

- | | |
|--------------------------------------|--|
| Lavoro o posizione ricoperti | <ul style="list-style-type: none">- Dal 1985 ha lavorato presso l'Unità Operativa di Ematologia di Vicenza, dapprima come borsista, quindi, dal 1989 come Assistente e quindi in qualità di Aiuto, poi Dirigente I livello, ricoprendo l'incarico di . Responsabile di Unità Operativa Semplice "Gestione attività ambulatoriale e di day hospital" (dal 2015) e di Vicario del Direttore (dal 2015)- Dal 1/9/2020 Direttore UOC Oncoematologia AULSS7 Pedemontana, Ospedale San Bassiano, Bassano del Grappa (delibera del DG del 27/5/2020)- |
| Principali attività e responsabilità | <ul style="list-style-type: none">- Attività clinica ambulatoriale e di reparto.- Speciale interesse DI RICERCA nelle leucemie acute, aplasia midollare, emoglobinuria parossistica notturna, anemie emolitiche. |

Nome e indirizzo del datore di lavoro	AULSS 7 "Pedemontana"– via dei Lotti 40, 36061 Bassano del Grappa (Vicenza), Italia
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Istruzione e formazione

- Diploma di Maturità Classica (luglio 1979)
- Laurea in Medicina e Chirurgia (11 marzo 1985)
- Diploma di specializzazione in ematologia clinica e di laboratorio (luglio 1988)
- Corso di formazione manageriale (SDA Bocconi – 2011-2012)

Principali tematiche/competenze professionali possedute

Attività di formazione:

- organizzazione e responsabilità scientifica di eventi formativi periodici (Corsi residenziali in Ematologia; Corsi di educazione continua in Ematologia) per Medici specialisti del territorio regionale

Attività scientifica:

- Più di 90 pubblicazioni su riviste internazionali
- Coordinatore della ricerca regionale finalizzata 826/02/98: "Assistenza specialistica decentrata per i pazienti anziani con leucemia acuta mieloide (LAM) e per pazienti con mieloma multiplo (MM) trattati con schemi polichemioterapici aplastizzanti"
- Referente per la rete ematologica della provincia di Vicenza
- Collaborazione con Gruppi cooperativi nazionali ed internazionali (GIMEMA, EBMT)
- Referente della Rete Ematologica Veneta per la patologia del globulo rosso

Capacità e competenze personali

Madrelingua(e)

Italiano

Altra(e) lingua(e)

Autovalutazione

Livello europeo (*)

Inglese

Spagnolo

Comprensione		Parlato		Scritto
Ascolto	Lettura	Interazione orale	Produzione orale	
B1	B1	B1	B1	B1
B1	B1	B1	B1	A2

(*) [Quadro comune europeo di riferimento per le lingue](#)

Capacità e competenze informatiche

Creazione ed elaborazione dati con vari supporti informatici (Excel, Assist, SPSS, Stata)

Capacità e competenze artistiche

Altre capacità e competenze

Patente

B

Ulteriori informazioni

Allegati

Firma

Bassano del Grappa, 24 settembre 2025

Autorizzo il trattamento dei miei dati personali ai sensi del Decreto Legislativo 30 giugno 2003, n. 196 "Codice in materia di protezione dei dati personali" e GDPR 679/16.

CURRICULUM VITAE - 2023

NAME **Lucio Luzzatto**
DATE/PLACE OF BIRTH September 28, 1936 Genova, Italy
NATIONALITY Italian
MARITAL STATUS Married with Paola Caboara Luzzatto; children Stefano & Fatima
e-mail: <lucio.luzzatto@unifi.it>
PRESENT POSITION Honorary Professor, University of Florence, Firenze, ITALY
MEDICAL LICENCE 1960 Italy
1965 Nigeria
1981 United Kingdom
1995 New York State
2016 Tanzania
BOARDS 1962 Hematology
1982 FRCPath
1983 FRCP
EDUCATION
1953 Maturità Classica, Liceo D'Oria, Genova, Italy,
1959 University of Genova Medical School M.D., Genova, Italy,
1968 Libera Docenza (PhD) in Biochemistry, Ministry of Education, Italy,
POSTGRADUATE CLINICAL AND RESEARCH TRAINING
1959-62 Resident, Department of Infectious Diseases, Ospedale S. Martino, Genova;
Research Fellow (part-time), Department of Biochemistry (2 years), then
Department of Biophysics (1 year), University of Genova, Genova, Italy
1963-64 Fellow in Haematology, Department of Medicine, College of Physicians & Surgeons,
Columbia Presbyterian Hospital, New York, NY, USA.
1964-67 Lecturer in Haematology, in charge of Blood Transfusion Unit Department of
Pathology, University of Ibadan, Ibadan, Nigeria.
POSITIONS AND APPOINTMENTS
1967-68 Senior Lecturer in charge of Sub-Department of Haematology, University of Ibadan,
Ibadan, Nigeria; Consultant Haematologist, UCH, Ibadan, Nigeria,
1968-1974 Professor of Haematology (from 1970 Head of Department) University of Ibadan,
Ibadan, Nigeria.
1974-1981 Director, International Institute of Genetics and Biophysics, CNR, Napoli, Italy,
1981-1994 Professor of Haematology (University of London), and Director of Haematology
Department, Royal Postgraduate Medical School (now Imperial College), London;
Consultant Haematologist, Hammersmith Hospital,
1994-2000 Chairman, Department of Human Genetics, Courtney Steel Chair, Attending
Physician in Genetics and Hematology, Memorial Sloan-Kettering Cancer Center;
Member of the Cell Biology and Genetics Programme, Sloan-Kettering Institute,
Professor of Medicine and Human Genetics, Cornell-Weill University Medical
College, New York, NY, USA.
2000-2004 Scientific Director, National Institute for Cancer Research, Genova, Italy,
2002-2006 Professor of Haematology, DOBIG, University of Genova, Genova, Italy
2005-2015 Scientific Director, Istituto Toscano Tumori, Florence, Italy
2015-2022 Professor of Haematology, Muhimbili University College of Health and Allied
Sciences (MUHAS), Dar-es-Salaam, Tanzania.
2006- Professor of Haematology (Honorary since 2008), University of Florence, Firenze,
Italy.
HONORARY DEGREES

- *Laurea ad honorem* in Pharmacy, University of Urbino, Italy, 1990
- DSc, University of Ibadan, Nigeria, 1998
- *Laurea ad honorem* in Medicine, University of Patras, 2006.

HONORS/ AWARDS (PARTIAL LIST)

- Pius XI Medal, 1976
- Sanremo International Prize for Human Genetics, 1982
- Ham-Wasserman Lecture, American Society of Haematology, San Francisco, CA, USA, 1988
- Oliver-Sharpey Lecture, Royal College of Physicians, 1988
- Adolfo Ferrata Lecture, Italian Society of Haematology, Rome, Italy, 1989
- Premio Napoli, 1995
- Nigerian Society of Haematology and Blood Transfusion: 25th Year Jubilee Lecture, 1997
- Fifth William C. Maloney Lecture, Brigham and Women's Hospital, Boston, MA, 1998
- Lilly Lectures - Royal College of Physicians, London and Sheffield, UK, 1999
- Premio Pier Camillo Beccaria, Associazione Angela Serra, Modena, Italy, 1999
- Premio Liguria, 2000
- James Blundell Award, British Society of Blood Transfusion, 2001
- Josè Carreras Lecture - European Haematology Association, Firenze, 2002
- Foreign Member, American Academy of Arts and Sciences, 2004.
- Montalenti Medal, University of Rome, 2007.
- Premio Giovanni Maria Pace, Trieste, 2007.
- Scientific Prize Accademia delle Scienze of Torino, 2011.
- Serafino Zappacosta Memorial Lecture, Napoli, 2012.
- Address to International Leaders in Haematology, ASH, Orlando, FL, USA, 2015
- Accademia dei Lincei Annual Scientific Prize for Biology, 2015.
- Environmental Mutagenesis and Genomics Society PIG-A Award, 2016

OTHER (PARTIAL LIST)

- Director, WHO Regional Reference Centre (Africa) for glucose-6-phosphate dehydrogenase: Ibadan 1967-74; Naples, 1976-1981
- Member (Chairman from 1983) of Steering Committee of Scientific Working Group on Biomedical Sciences, Special Programme on Tropical Diseases, WHO, 1978-86
- Member National Cancer Advisory Board - Ministry of Health, Italy, 2000
- Member National Advisory Board on Stem Cell Research - Ministry of Health, Italy, 2000
- Member of Scientific Committee, Science Festival, Genova, 2003-2012
- Member of Life Sciences Panel 7, European Research Council, Bruxelles, 2008-2016
- Chair, Scientific Advisory Committee, Italian Cystic Fibrosis Foundation, 2012-2015
- Chair, Scientific Advisory Committee, Josep Carreras Institute, Barcelona, 2013-2023
- Chair, WHO Evidence Review Group on Point of Care G6PD Testing to Support Safe Use of Primaquine for the Treatment of Vivax Malaria, Geneva, 2014
- Member, WHO Technical Consultation on G6PD, 2022
- Member of Global Award Sub-Committee, American Society of Hematology, 2018-2020.
- Foreign Member, *Accademia Nazionale dei Lincei*, 2021.

The *leitmotiv* of Lucio Luzzatto's research and teaching has been the understanding of human disease at the molecular level; particularly in the area of blood diseases, for the ultimate purpose to improve their management. LL and colleagues cloned the human *G6PD* gene in the early eighties, thus laying foundations for the molecular pathophysiology and population genetics of G6PD and G6PD deficiency. In the area of malaria, beyond pioneering the work that indicated that heterozygotes for G6PD deficiency are protected against mortality for *P falciparum*, LL has opened insights on the mechanism of malaria selection with respect to both the sickle cell trait and G6PD deficiency. LL first provided evidence that paroxysmal nocturnal haemoglobinuria (PNH) is a clonal disorder, introduced the concept of conditional clonal selection and provided supporting evidence: thus rationalising the relationship of clonal expansion with bone marrow failure, and with the treatment of PNH. In summary, LL has devoted his research to contemporary molecular medicine.

PUBLICATIONS

444 scientific papers listed in *PubMed*. Many chapters in major textbooks.

1 Book for lay people: *CAPIRE IL CANCRO (UNDERSTANDING CANCER)*, Publ. Rizzoli, 2006; Paperback edition (BUR), 2009.

**INFORMAZIONI
PERSONALI****Monica Mazzucato**

✉ monica.mazzucato@regione.veneto.it

Sesso F | Data di nascita 13/10/1974 | Nazionalità Italiana

**ESPERIENZA
PROFESSIONALE****01/06/2012–alla data
attuale**

Dirigente Medico r.e. Coordinamento malattie rare - Regione del Veneto - Azienda Ospedale Università di Padova

**ISTRUZIONE E
FORMAZIONE**31/03/2000 Laurea in Medicina e Chirurgia (con pieni voti)
Università degli Studi di Padova01/12/2000 Abilitazione all'esercizio della professione di medico chirurgo
Università degli Studi Padova01/01/2002–01/01/2003 Corso di Perfezionamento "Pediatria nei Paesi in via di Sviluppo"
Università degli Studi di Padova20/12/2004 Specializzazione in Medicina di Comunità (con pieni voti e lode)
Università degli Studi di Padova16/04/2008 Dottore di Ricerca in "Medicina dello Sviluppo e Scienze della
Programmazione-indirizzo Scienze della programmazione",
Università degli Studi di Padova27/07/2020 Master universitario di II Livello
in Economia e Management dei Servizi Sanitari nell'a.a. 2019/2020
Università degli Studi di Padova14/07/2020 Certificato di formazione manageriale per le funzioni di direzione di struttura
complessa, rilasciato ai sensi degli artt. 15 e 16-quinquies del
D.Lgs. n. 502/1992 e s.m.i., dell'art. 7 del D.P.R. n. 484/1997,
Università degli Studi di Ferrara**COMPETENZE
PERSONALI**

Lingua madre Italiano

Altre lingue

Inglese

COMPRESIONE		PARLATO		PRODUZIONE SCRITTA
Ascolto	Lettura	Interazione	Produzione orale	
C1	C1	C1	C1	C1

Competenze comunicative

competenze comunicative acquisite durante le attività di docenza a corsi universitari e non, durante la partecipazione come relatore a numerosi corsi e congressi e nello svolgimento dell'attività di supervisore di un Centro informazioni sulle malattie rare parte del Network europeo dedicato rivolto a professionisti e pazienti

Competenze organizzative e gestionali

- leadership (coordinamento di gruppi di lavoro, supervisione come tutor dell'attività di medici in formazione Scuola di Specialità in Medicina di Comunità e delle cure primarie, coordinamento delle attività del Centro informazioni regionale sulle malattie rare)
- gestione di work-packages nell'ambito di progetti nazionali ed europei

Competenze professionali

competenze di programmazione sanitaria
competenze di carattere epidemiologico
competenze di ricerca

Competenze digitali

AUTOVALUTAZIONE				
Elaborazione delle informazioni	Comunicazione	Creazione di Contenuti	Sicurezza	Risoluzione di problemi
UTENTE AVANZATO	UTENTE AVANZATO	UTENTE AUTONOMO	UTENTE AUTONOMO	UTENTE AUTONOMO

Patente di guida

B

ULTERIORI INFORMAZIONI

Dati personali

Autorizzo il trattamento dei miei dati personali ai sensi del Decreto Legislativo 30 giugno 2003, n. 196 "Codice in materia di protezione dei dati personali". Dichiaro inoltre di essere informato ai sensi e per gli effetti dell'art. 13 del D.lgs 196/2003, che il presente curriculum verrà pubblicato nella banca dati presente nel sito <https://salute.regione.veneto.it> e a tal fine acconsento al trattamento dei dati personali contenuti.

Dr.ssa Monica Mazzucato

Padova 24.07.2025



CURRICULUM VITAE

Rosario Notaro born in Portici (Naples) on 8th of March 1956

Licensed Physician:	Year: 1988	Place of Issue: Naples, Italy
Board Certification	Year: 1992	Name: Hematology
License N. 13610 (Florence, Italy)		FISCAL ID: NTRRSR56C08G902M

Present Appointment:

Since August 2021: Director of Core Research Laboratory - Istituto per lo Studio, la Prevenzione e la Rete Oncologica (ISPRO), Florence, Italy.

Since February 2018: Dirigente Medico I livello (Attending), Principal Investigator of Laboratory of Cancer Genetics and Gene Transfer, Core Research Laboratory – Istituto per lo Studio, la Prevenzione e la Rete Oncologica (ISPRO), Florence, Italy.

Since February 2018: Consultant of University Hospital (Azienda Ospedaliero-Universitaria) Careggi (Florence, Italy) to run the *PNH and Related Disorders Outpatient Service* in the Department of Hematology

Working address:

Laboratory of Cancer Genetics and Gene Transfer,
Core Research Laboratory – Istituto per lo Studio, la Prevenzione e la Rete Oncologica (ISPRO)
Viale Pieraccini 6 (Cubo 3) – 50139 Firenze (Italia)

Appointments:

1995-2000: Research Fellow, Department of Human Genetics, Memorial Sloan-Kettering Cancer Center, New York, USA

1999-2001: Assistant Professor of Medicine, Cornell University Medical School, New York, USA

2001- February 2007: “Dirigente Medico I livello”, Laboratory of Human Genetics, IST, Istituto Nazionale per la Ricerca sul Cancro, Genoa, Italy.

2003- February 2007: Chief of Regional Reference Center for Paroxysmal Nocturnal Hemoglobinuria, IST, Genoa, Italy.

March 2007 – January 2018: Dirigente Medico I livello (Attending), Principal Investigator of Laboratory of Cancer Genetics and Gene Transfer, Core Research Laboratory - Istituto Toscano Tumori, AOUC, Florence, Italy.

June 2011 – January 2018: Deputy Director (Direttore *f.f.*) of Core Research Laboratory - Istituto Toscano Tumori, AOUC, Florence, Italy.

December 2019 – July 2021: Deputy Director (Direttore *f.f.*) of Core Research Laboratory - Istituto per lo Studio, la Prevenzione e la Rete Oncologica (ISPRO), Florence, Italy.

Education:

1988, M.D., First Class Honors, University “Federico II” of Naples, Italy

Postdoctoral Training:

1988-1995, Department of Hematology, University “Federico II” of Naples, Italy

1988-1995, Cell Culture Laboratory, Department of Hematology, University “Federico II” of Naples,

AWARDS AND HONORS:

Fellowship from Associazione Italiana per la Ricerca sull'Anemia di Fanconi (AIRFA): “Saggi clonogenici e test di eritrofagocitosi nell'Anemia di Fanconi”. March-August **1991**; January-June **1992**; September **1992** – April **1993**.

Member of the Editorial Board of “Haematologica – The Hematology Journal”: **2008-2015**.

Member of the Scientific Board of the “Associazione Italiana EPN” (Association of Italian PNH Patients) since **2010**.

Member of the Review Committee of the “Database EPN - Istituto Superiore della Sanità” (Database of Italian PNH Patients at National Institute of Health) since **2014**

Member of the Scientific Board of the 19th International Fritz-Bender Foundation Symposium. Pisa, July 1-2, **2015**.

President of the international meeting Paroxysmal Nocturnal Hemoglobinuria: the crossroads of somatic mutations, clonal expansion and immunity. Florence (Italy), October 3-4, 2024

SCIENTIFIC AND MEDICAL SOCIETIES:

Member, Italian Society of Experimental Hematology

Member, Italian Society of Hematology

REVIEWER FOR INTERNATIONAL JOURNALS:

Acta Obstetricia et Gynecologica Scandinavica (AOGS),

American Journal of Hematology,

Annals of Hematology,

Blood,

Blood Advance,

British Journal of Haematology,

Clinical Chemistry,

Circulation,

Current Stem Cell Research & Therapy,

eJHaem

European Journal of Nutrition,

Experimental Hematology,

Haematologica – The Hematology Journal,

Hematology,

Hemasphere,

Human Immunology,

Journal of Biotechnology,

Journal of Hematology and Oncology,

Molecular & Cellular Probes,

Nature Reviews Disease Primers,

Oncogene,

Oncotarget,
Plos Neglected Infectious Disease,
Transfusion and Apheresis Science,
Trends in Pharmacological Sciences
Grant reviewer for French National Cancer Institute (INCa).

CLINICAL TRIALS

PRINCIPAL INVESTIGATOR:

Observational Prospective Study. NCT04854343. SLPI: a Novel Biomarker of Prostate Cancer. Exploratory study of SLPI expression in human prostate cancer patients.

SUB INVESTIGATOR:

Phase 2. Eudract: 2016-003526-16; NCT03472885A. A phase 2 open-label study of ACH-0144471 in patients with Paroxysmal Nocturnal Hemoglobinuria (PNH) who have an inadequate response to eculizumab monotherapy. Achillion, ACH471-101.

Phase 2. Eudract: 2019-003830-17; NCT04170023. A phase 2 open-label proof of concept study to assess the efficacy, safety, and pharmacokinetics of the oral Factor D (FD) inhibitor ALXN2050 (ACH-0145228) in Paroxysmal Nocturnal Hemoglobinuria (PNH) patients as monotherapy. Alexion, ACH228-110.

Phase 2. Eudract: 2019-003830-17; NCT04170023. A Phase 2 Open-Label Proof of Concept Study to Assess the Efficacy, Safety, and Pharmacokinetics of the Oral Factor D (FD) Inhibitor ACH-0145228 in Paroxysmal Nocturnal Hemoglobinuria (PNH) Patients as Monotherapy and with an Approved C5 Inhibitor as Background Therapy. Alexion, ACH471-103.

Phase 3. Eudract: 2019-003829-18; NCT04469465. A phase 3 study of danicopan (ALXN2040) as add-on therapy to a C5 inhibitor (eculizumab or ravulizumab) in patients with Paroxysmal Nocturnal Hemoglobinuria (PNH) who have clinically Evident Extravascular Hemolysis (EVH). Alexion, ALXN2040-PNH-301.

Phase 3. Eudract: 2016-002025-11; NCT02946463. A phase 3, randomized, open-label, active-controlled study of ALXN1210 versus eculizumab in complement inhibitor treatment-naïve adult patients with Paroxysmal Nocturnal Hemoglobinuria (PNH). Alexion, ALXN1210-PNH-301.

Phase 3. Eudract: 2016-002026-36; NCT03056040. A phase 3, randomized, open-label, active-controlled study of ALXN1210 versus eculizumab in adult patients with Paroxysmal Nocturnal Hemoglobinuria (PNH) currently treated with eculizumab. Alexion, ALXN1210-PNH-302.

Phase 3. Eudract: 2019-004665-40; NCT04558918. A randomized, multicenter, active-comparator controlled, open-label trial to evaluate efficacy and safety of oral, twice daily LNP023 in adult patients with PNH and residual anemia, despite treatment with an intravenous anti-C5 antibody. Novartis, CLNP023C12302.

Phase 3. Eudract: 2020-000597-26; NCT04432584. A phase 3, randomized, open-label, active-controlled, multicenter study evaluating the efficacy and safety of crovalimab versus eculizumab in patients with Paroxysmal Nocturnal Hemoglobinuria (PNH) currently treated with complement inhibitors. Roche, BO42161.

Phase 3. Eudract: 2019-004931-21; NCT04434092. A phase 3, randomized, open-label, active-controlled, multicenter study evaluating the efficacy and safety of crovalimab versus eculizumab in patients with Paroxysmal Nocturnal Hemoglobinuria (PNH) not previously treated with complement inhibitors. Roche, BO42162.

Phase 3. Eudract: 2020-004486-40; NCT04162470. A randomized, open-label, C5 inhibitor-controlled study to evaluate the efficacy and safety of pozelimab and cemdisiran combination therapy in patients with Paroxysmal Nocturnal Hemoglobinuria who are complement inhibitor treatment-naïve or have not recently received complement inhibitor therapy. Regeneron, R3918-PNH-2021.

Phase 3b. Eudract: 2021-004253-22; NCT05389449. A Long-Term Extension (LTE) study to characterize the safety and efficacy of danicopan as an add-on therapy to a complement component 5 inhibitor (C5i) in patients with Paroxysmal Nocturnal Hemoglobinuria (PNH) previously treated with danicopan in an Alexion-sponsored clinical study. Alexion, ALXN2040-PNH-302.

Phase 3b. Eudract: 2020-004385-19; NCT04747613. An open label, multicenter Roll-over Extension Program (REP) to characterize the long-term safety and tolerability of iptacopan (LNP023) in patients with Paroxysmal Nocturnal Hemoglobinuria (PNH) who have completed PNH Phase 2 and Phase 3 studies with iptacopan. Novartis, CLNP023C12001B.

Phase 3b. Eudract: 2022-502148-10-00; NCT0563001. A multicenter, single arm, open-label trial to evaluate efficacy and safety of oral, twice daily iptacopan in adult PNH patients who have Hb $\geq$ 10 g/dL in response to anti-C5 antibody and switch to iptacopan. Novartis, CLNP023C12303.

Phase 3b. Eudract: 2021-004931-10; NCT05744921. Open-Label Extension Study to Evaluate the Long-Term Safety, Tolerability, and Efficacy of Pozelimab and Cemdisiran Combination Therapy in Patients with Paroxysmal Nocturnal Hemoglobinuria. Regeneron, R3918-PNH-2050.

Observational study to evaluate patient-reported outcomes in Paroxysmal Nocturnal Hemoglobinuria (PNH): QOL-ONE PRO-PNH.

TEACHING EXPERIENCE

Responsible for organizing and teaching the course of Genetics–“Gene Structure and Expression”–for medical students at “Cornell University Medical College”, New York, April 5-30, **1999**.

Supervisor of the stage at IST (Genova) of students from "Master in Biothechnology applied Oncology - DIMOTECH", University of Bari, **2004**.

PhD student supervisor for the “Doctoral program in Biology and Genetics” University of Genova (Italy). **2002-2005**.

Lecture for the PhD students of “Doctoral School in Molecular Medicine”, University “Federico II”. Naples April 15, **2007**.

Lecture for the “Master in Transfusion Hematology”. Florence April 18, **2007**

Series of 4 educational lectures for hematologist about “Management of Paroxysmal Nocturnal Hemoglobinuria: update in diagnosis and treatment”. Roma, Torino, Catania, Napoli. May-June **2009**

Lecture for the residential course “Clonal and immuno-mediated hematopoietic diseases”. Florence September 21, **2010**

Lectures for graduate students participating to the ERASMUS program at the University of Firenze (Italy) 21 October 21, **2009**

October 18, **2010**

October 23, **2012**

March 26, **2014**

Member of the Faculty Board of the “Doctorate in Genetics, Oncology and Clinical Medicine (GenOMeC)”, University of Siena (Italy) since **2015**.

Thesis Supervisor for Undergraduate, Graduate and Medical Residency programs. University of Florence (Italy): 2010-today.

COMMUNICATION AND PATIENT’S DAYS

Festival dell'identità Toscana –Una sanità che fa bene: cure, esiti e tutela del diritto alla salute in Toscana
Palazzo del Pegaso, Firenze, 28 aprile **2025**
La Rete Oncologica Toscana - La Ricerca di base nel SSR

Emoglobinuria Parossistica Notturna, Molte Terapie per una Malattia Rara? I pazienti incontrano i loro Medici".
Osp. San Bassiano, Bassano del Grappa, 26 novembre, **2022**
Patient's day

Emoglobinuria Parossistica Notturna: *Giornata EPN – Patient's day*
Incontro Virtuale, 9 gennaio, **2021**
Gli unmeet clinical need

Emoglobinuria Parossistica Notturna: *Giornata EPN – Patient's day*
Milano, 11 Maggio, **2019**
Diagnosi, fisiopatologia e clinica dell'EPN

Emoglobinuria Parossistica Notturna: *Giornata EPN – Patient's day*
Torino, 12 gennaio, **2019**
*Che cos'è l'Emoglobinuria Parossistica Notturna
inquadramento e nuovi sviluppi nella terapia e nella ricerca*

Emoglobinuria Parossistica Notturna: *Vivere con l'EPN*

Roma, 5 novembre **2016**

Nuovi sviluppi nella terapia e nella ricerca

Giornata EPN – *patient's day*

Torino, 19 ottobre **2015**

EPN: Nuovi sviluppi nella terapia e nella ricerca

Emoglobinuria Parossistica Notturna: *Incontro Medici-Pazienti*

Vicenza, 19 novembre **2014**

EPN: stato dell'arte

Emoglobinuria Parossistica Notturna: *Vivere con l'EPN - Giornata per i Pazienti*

Firenze, 26 ottobre **2013**

Recenti sviluppi nella pratica clinica

Emoglobinuria Parossistica Notturna: +conoscenza +esperienza - Incontro Medici-Pazienti

Vicenza, 11 giugno **2012**

EPN: stato dell'arte

Emoglobinuria Parossistica Notturna; *Pazienti ed EPN: ... il viaggio continua ..*

Roma, 18 giugno **2011**

Novità e Ricerche in Corso nell'EPN

Emoglobinuria Parossistica Notturna: 2nd Patient's Day

Milano, 27 marzo **2010**

Novità nell'EPN

Emoglobinuria Parossistica Notturna: una giornata con i pazienti

Firenze, 28 Febbraio **2009**

Che cos'è L'EPN

INVITED LECTURES

Malattie Rare in Ematologia non Neoplastica: Sfide e Prospettive Terapeutiche

Firenze, November 12, **2025**

EMOGLOBINURIA PAROSSISTICA NOTTURNA- Stato dell'arte e nuove prospettive terapeutiche

ISPRO Oggi e Domani

Firenze, October 30, **2025**

Ricerca e sperimentazioni

OUT OF THE MAZE, From Misdiagnosis To Mastery A New Era In PNH Starts Here

Dubai (UAE), Sep 12-13, **2025**

a) Clones, Cells & Clinical Consequences: The Hidden Drivers of PNH

b) Dissecting Breakthrough Hemolysis. A Pathophysiologic Perspective of PNH

c) Redefining PNH: Treatment Priorities & Monitoring

Advanced Treatments in the real-life of Coagulation and Red Cells Rare Disorders,

GARDEN (Global Hematological Rare Diseases Alliance) Webinars Series, Sep 6, **2025**

L'inibizione del complemento nella PNH: terminale e doppia inibizione – Le basi biologiche

COMPLEMENTary

Milano, May 28, **2025**

L'inibizione del complemento nella PNH: terminale e doppia inibizione – Le basi biologiche

La Ricerca in Oncologia

Firenze, May 16, **2025**

C.R.L. – Clonality Role: a mutable Landscape

2025 Korean Society of Hematology International Conference and 60th Annual Meeting (ICKSH2025)

Seoul (South Korea), March 28, **2025**

Optimal treatment of PNH In the era of proximal complement inhibitors

Paroxysmal Nocturnal Hemoglobinuria: the crossroads of somatic mutations, clonal expansion and immunity.

Florence (Italy), October 3, **2024**

C3 binding in PNH patients treated with C5 inhibitors

2nd International Florence Symposium from Genes to Target Therapy in Hematology

Florence (Italy), April 18th, **2024**

Moving towards second generation drugs for PNH

Complement Masters: Paroxysmal Nocturnal Haemoglobinuria (PNH)

Paris (F), November 17 & 18, **2023**

IVH, EVH, BTH – fundamentals in haemolysis in PNH

50° Congresso Nazionale SIE – Meeting Educazionali

Roma (IT), October 23 & 25, **2023**

Meeting Educazionali - *Sindromi da insufficienza midollare: Mutazioni somatiche nelle sindromi da insufficienza midollare*

International Workshop Complement System: Rare Diseases and targeted therapies

Palermo (IT), October 14, **2023**

Paroxysmal Nocturnal Hemoglobinuria

3° Corso “Gestione delle malattie rare nel 2023”.

Firenze (IT), October 5, **2023**

Emoglobinuria Parossistica Notturna: dalla fisiopatologia alle nuove prospettive terapeutiche

Congresso QOL-ONE SIES- Aggiornamenti dall'EHA 2023

Reggio Calabria (IT), July 6, **2023**

Nuovi inibitori del complemento

1st International IPIG Conference

Harrogate (UK), May 19, **2023**

Proximal inhibitors: monotherapy vs combination treatment

1ST Symposium on Innovative Therapies in Hematology

Avellino, March 30, **2023**

Improving terminal complement inhibitors for PNH

Simposio Emoglobinuria Parossistica Notturna (EPN)

Milano, March 7 marzo, **2023**

Inibitori del complemento di nuova generazione

INC3PTION – Per le persone con EPN inizia una nuova storia.

Milano, January 23, **2023**

Meccanismi d'azione degli inibitori del complement

International Symposium "From Genes To Target Therapy In Hematology – A Meeting To Celebrate 50+2 Years Of The Hematology Department In Florence.

Florence, July 1, **2022**

Complement-driven anemia: the lesson of PNH

European Haematology Association –

EHA2021 Virtual Congress, June 9-17, **2021**

Thematic Debate: *Treatment options in PNH*

Bone Marrow Failure Disorders – from the cell to the cure of disease. ESH European School of Haematology - Translational Research E-Conference, November 12, **2020**

Pathophysiology of PNH

L'accesso alle terapie per le malattie rare - IV edizione,

– Corso FAD “on air” from October 9, 2020

L'Emoglobinuria Parossistica Notturna

Time is Life – Ravulizumab nella terapia della EPN

Virtual Meeting, September 11, **2020**

Il sistema del complemento nell'EPN

V Convegno di Ematologia non Maligna

Florence, January 31, **2020**

Aggiornamenti su EPN

XXXIV Congresso della Società Italiana di Farmacologia

Florence, Feb 16, 2026

Florence, November 22, **2019**

A new landscape in complement inhibition for PNH: from pharmacology to the clinical practice

Le Malattie Rare in Ematologia: Emoglobinuria Parossistica Notturna e malattia di Gaucher

Florence, November 20, **2019**

Terapia oggi e nuove prospettive terapeutiche

Le reazioni avverse al cibo: intolleranze e allergie alimentari

Roma, October 4, **2019**

Il Favismo

The New Era of Aplastic Anemia and Paroxysmal Nocturnal Hemoglobinuria -in memory of our friend Bruno Rotoli-

Napoli, May 16, **2019**

The complement system and PNH

X Congresso Nazionale SITE

Roma, September 27, **2018**

Club del globule rosso: *PNH – EPN, Emoglobinuria Parossistica Notturna*

Renaissance: Shaping the future in Aplastic Anemia

Roma, April 6, **2018**

Fisiopatologia dell'Aplasia Midollare

GenOMeC seminars, 2018 series

Siena, Firenze, Pisa, February 12, **2018**

Paroxysmal Nocturnal Hemoglobinuria; at the crossroads of somatic mutations, clonal expansion and immunity

UpDate in Ematologia 2017

Genova, December 15, **2017**

Malattie ematologiche complemento mediate

Malattie Rare non Neoplastiche in Ematologia,

Firenze, November 10, **2017**

Le Aplasie Midollari, Inquadramento fisiopatologico

46° Congresso SIE,

Roma, October 16 & 17, **2017**

Meeting Educazionali. *Aplasie midollari: Fisiopatologia, alterazioni immunologiche e lesioni geniche*

10th International Conference on Complement Therapeutics

Heraclion (Greece), July 28, **2017**

Intra and extra vascular hemolysis in Paroxysmal Nocturnal Hemoglobinuria (PNH): a never-ending hike between beds and benches.

Città della Salute e della Scienza di Torino, University of Turin Medical School.

Turin, March 21, **2017**

Paroxysmal Nocturnal Hemoglobinuria

Hematology 2017 - La medicina di precisione del futuro

Milan, March 4, **2017**

Acquired Aplastic Anemia – Pathophysiology

Florence, Feb 16, 2026

3rd Meeting Le Malattie Rare in Ematologia non Oncologica
Florence, January 27, **2017**
La gravidanza in PNH

ASSOMAGI and GENOMECC joint seminar
Bozen, September 23, **2016**
Somatic mutation rate and cancer

DENOTHE SEMINARS
Florence, April 26, **2016**
Paroxysmal Nocturnal Hemoglobinuria: much more than Hemolysis

6th European Symposium on Rare Anaemias - ENERCA
Amsterdam (The Netherlands), November 22, **2015**
Paroxysmal Nocturnal Hemoglobinuria (PNH) - Introduction to PNH

Le Malattie Rare in Ematologia non Oncologica - dagli aspetti organizzativi alle terapie innovative
Florence, October 23, **2015**
Il lungo viaggio dell'EPN, dal rischio aplastico al rischio trombotico

2nd International Workshop on Orphan Drugs
Ranica (BG), September 8, **2015**

10th Annual Scientific Conference - Istituto Toscano Tumori
Pisa, July 3, **2015**
From PNH to AML

EBMT SAAWP-IDWP Joint Educational meeting - Memorial Bruno Rotoli
A Special Focus on PNH
Naples, September 30, **2014**
Ecuzumab and PNH

EHA-ESH Hematology Tutorial - Diagnostic Work-Up of Hematological Diseases, Focus on Red Cells
Rome, February 7 –9, **2014**
Paroxysmal Nocturnal Hemoglobinuria

8th Annual Scientific Conference - Istituto Toscano Tumori
Cortona, July 5, **2013**
The Somatic mutation rate

International PNH Interest Group, 7th Annual Scientific Assembly
Atlanta (Georgia, USA), December 7, **2012**
Genetics of Clinical Response to Ecuzumab

DENOTHE and ITT joint seminar: Cancer genomics update
Florence, May 8, **2012**
Full Sequencing of Tumor Samples: Concepts and Principles

Workshop Erythropoïèse. Alliance nationale pour les sciences de la vie et de la santé. Boutigny sur Essonne, June 29, **2011**
Paroxysmal Nocturnal Hemoglobinuria: clonal expansion

Biotechnology and Medicine. University of Pisa.
Pisa, November 26, **2010**
Cancer genetics.

42nd National Meeting of SIBIOC (Italian Society of Laboratory Medicine).

Florence, Feb 16, 2026

Roma, October 8, **2010**

Inherited anemias: classification and diagnosis.

4th Annual Scientific Conference - Istituto Toscano Tumori

Pisa, July 3, **2009**

Paroxysmal Nocturnal Hemoglobinuria.

Hot Topics nella terapia adiuvante del carcinoma mammario – Workshop del Gruppo Italiano Mammella (GIM)

Rome, May 19, **2008**

Ruolo dei polimorfismi del CYP19 nella terapia ormonale.

2nd Annual Scientific Conference - Istituto Toscano Tumori

Firenze, July 6, **2007**

Polymorphisms of UGT1A family genes and cancer chemotherapy

9th International Symposium on Myelodysplastic Syndromes.

Firenze, May 18, **2007**

Paroxysmal Nocturnal Hemoglobinuria.

University “Federico II” Medical School, Interdepartmental Seminars Series.

Napoli, April 13, **2007**

Paroxysmal Nocturnal Hemoglobinuria.

Recent progress in stem cell research and regenerative medicine.

Genova, March 15, **2007**

Gene Transfer into Hematopoietic Stem Cells

International workshop on Immune-mediated marrow failure.

Napoli, June 20, **2006**

Paroxysmal Nocturnal Hemoglobinuria: immune derangement in PNH

10th National Conference of AIOM (Italian Medical Oncology Association) - Breast Cancer.

Genova, April 19, **2005**

Recent biological insights and clinical implications of: therapeutic tailoring.

9th Meeting of European Society of Gene Therapy -Educational session-.

University of Torino Medical School, Department of Genetics.

Torino, May 21, **2003**

Paroxysmal Nocturnal Hemoglobinuria: dynamics of hematopoietic clones.

Myelodysplastic syndromes: from bench to bedside.

Torino, June 4, **2002**

Flow-cytometry diagnosis of Paroxysmal Nocturnal Hemoglobinuria.

University of Milano Medical School, Institute of Internal Medicine.

Milano, April 5, **2002**

Deficiency of glucose 6-phosphate dehydrogenase: from genetics to gene therapy.

9th Meeting of European Society of Gene Therapy -Educational session-.

Antalya, November 1, **2001.**

Gene therapy of haematological diseases

La Clinica dell’Anemia di Fanconi: Realtà, Quesiti e Prospettive – A.I.R.F.A

Napoli, March 3, **1995.**

Anemia di Fanconi: Stress ossidativo ed ematopoiesi

Leucemia Mieloide Cronica – dalle conoscenze biologiche al progresso terapeutico

Florence, Feb 16, 2026

Napoli, June 25, **1994**.
Un caso clinico

PUBLICATIONS

JOURNAL ARTICLES

104 articles published in peer-reviewed journals, with a total Impact Factor of **1378,2** (ISI Web of Knowledge, 2024). Number of citations: **5311**. H-index: **38** (Scopus, February 2026). First Author, 7 papers. Last and/or Corresponding Author 32 papers.

- 1) Rosini D, Cosi I, Moccia A, Nannelli C, De Iaco P, Sebastianelli A, Di Stefano G, Serni S, Nesi G, **Notaro R***, De Angioletti M. SLPI in prostate cancer. *Cancers* **2026** Feb;18(3):487. doi: 10.3390/cancers18030487. *Corresponding Author
- 2) Notaro R & Risitano AM. PNH extravascular hemolysis: exploring clinical significance. *Blood Advance* **2026**. Online ahead of print. doi: 10.1182/bloodadvances.2025019301.
- 3) Kulasekararaj AG, Browett PJ, Risitano AM, Patriquin CJ, Yenerel MN, Marceau D, Sahin F, Algarra L, Ogawa M, Yu J, Cross N, **Notaro R**, Lee JW, Brodsky RA. Efficacy and Safety of Vemircopan as Monotherapy in Patients With Paroxysmal Nocturnal Hemoglobinuria. *Blood Advance* **2026**. Feb 10;10(3):540-554. doi: 10.1182/bloodadvances.2025017731.
- 4) Cosi I, Moccia A, Nannelli C, Rosini D, Iozzo M, Sica M, Luceri C, **Notaro R***, De Angioletti M. ETV4 and ETV1-mediated downregulation of the secretory leukocyte protease inhibitor contributes to the indolent phenotype of early-stage prostate cancer. *Biochimica Biophysica Acta Molecular Basis of Diseases* **2025** Oct;1871(7):167975. doi: 10.1016/j.bbadis.2025.167975. *Corresponding Author
- 5) Risitano AM, Kulasekararaj AG, Scheinberg P, Röth A, Han B, Maciejewski JP, Ueda Y, de Castro CM, Di Bona E, Fu R, Zhang L, Griffin M, Langemeijer SMC, Panse J, Schrezenmeier H, Barcellini W, Mauad VAQ, Schafhausen P, Tavitian S, Beggiato E, Chew LP, Gaya A, Huang W-Han, Jang JH, Kitawaki T, Kutlar A, **Notaro R**, Pullarkat V, Schubert J, Terriou L, Uchiyama M, Lee LWL, Yap E-S, Frieri C, Marano L, Sicre de Fontbrune F, Gandhi S, Trikha R, Alashkar F, Yang C, Liu H, Kelly RJ, Höchsmann B, Lawniczek T, Mahajan N, Solar-Yohay S, Kerloëguen C, Ferber P, Kumar R, Wang Z, Thorburn C, Maitra S, Li S, Verles A, Dahlke M, de Latour RP. Oral iptacopan monotherapy in paroxysmal nocturnal haemoglobinuria: final 48-week results from the open-label, randomised, phase 3 APPLY-PNH trial in anti-C5-treated patients and the open-label, single-arm, phase 3 APPOINT-PNH trial in patients previously untreated with complement inhibitors. *Lancet Haematology*. **2025** Jun;12(6):e414-e430. doi: 10.1016/S2352-3026(25)00081-X.
- 6) Kulasekararaj A, Brodsky R, Schrezenmeier H, Griffin M, Röth A, Piatek C, Ogawa M, Yu J, Patel AS, Patel Y, **Notaro R**, Usuki K, Kulagin A, Gualandro S, Füreder W, Peffault de Latour R, Szer J, Lee JW. Ravulizumab demonstrates long-term efficacy, safety and favorable patient survival in patients with paroxysmal nocturnal hemoglobinuria. *Annals of Hematology*. **2025** Jan 22. doi: 10.1007/s00277-025-06193-5. PMID: 39841198.
- 7) Risitano AM, Frieri C, Marano L, Urciuoli E, Sanseverino A, Nannelli C, **Notaro R**. Massive hemolysis in paroxysmal nocturnal hemoglobinuria after switching from proximal complement inhibitor to anti-C5 therapy: A lesson not to be forgotten. *American Journal of Hematology*. **2025** Jan;100(1):163-167. doi: 10.1002/ajh.27502. PMID: 39394926.
- 8) Peffault de Latour R, Röth A, Kulasekararaj AG, Han B, Scheinberg P, Maciejewski JP, Ueda Y, de Castro CM, Di Bona E, Fu R, Zhang L, Griffin M, Langemeijer SMC, Panse J, Schrezenmeier H, Barcellini W, Mauad VAQ, Schafhausen P, Tavitian S, Beggiato E, Chew LP, Gaya A, Huang WH, Jang JH, Kitawaki T, Kutlar A, **Notaro R**, Pullarkat V, Schubert J, Terriou L, Uchiyama M, Wong Lee Lee L, Yap ES, Sicre de Fontbrune F, Marano L, Alashkar F, Gandhi S, Trikha R, Yang C, Liu H, Kelly RJ, Höchsmann B, Kerloeguen C, Banerjee P, Levitch R, Kumar R, Wang Z, Thorburn C, Maitra S, Li S, Verles A, Dahlke M, Risitano AM. Oral Iptacopan Monotherapy in Paroxysmal Nocturnal Hemoglobinuria. *New England Journal of Medicine*. **2024** 24 Mar 14;390(11):994-1008. doi: 10.1056/NEJMoa2308695. PMID: 38477987
- 9) Sica M, **Notaro R**. The inhibition of several components of terminal complement pathway results in C3-binding to PNH red cells. *American Journal of Hematology*. **2024** Mar;99(3):505-507. Doi: 10.1002/ajh.27215. PMID: 38264841.
- 10) Lee JW, Griffin M, Kim JS, Lee LW, Piatek C, Nishimura JJ, Carrillo Infante C, Jain D, Liu P, Filippov G, Sicre de Fontbrune F, Risitano A, Kulasekararaj AG; ALXN2040-PNH-301 Investigators (...**Notaro R**...).

Addition of danicopan to ravulizumab or eculizumab in patients with paroxysmal nocturnal haemoglobinuria and clinically significant extravascular haemolysis (ALPHA): a double-blind, randomised, phase 3 trial. *Lancet Haematology*. 2023 Dec;10(12):e955-e965. doi: 10.1016/S2352-3026(23)00315-0. PMID: 38030318.

- 11) Conte B, Boni L, Bisagni G, Durando A, Sanna G, Gori S, Garrone O, Tamberi S, De Placido S, Schettini F, Pazzola A, Ponzone R, Montemurro F, Lunardi G, **Notaro R**, De Angioletti M, Turletti A, Mansutti M, Puglisi F, Frassoldati A, Porpiglia M, Fabi A, Generali D, Scognamiglio G, Rossi M, Brasó Maristany F, Prat A, Cardinali B, Piccioli P, Serra M, Lastraioli S, Bighin C, Poggio F, Lambertini M, Del Mastro L. SNPs of aromatase predict long-term survival and aromatase inhibitor toxicity in patients with early breast cancer: a biomarker analysis of the GIM4 and GIM5 trials. *Clinical Cancer Research*. 2023 Dec 15;29(24):5217-5226. DOI: 10.1158/1078-0432.CCR-23-1568. PMID: 37888299.
- 12) Luzzatto L, Nannelli C, **Notaro R**. Potentially pathogenic and pathogenic G6PD variants. *American Journal of Human Genetics*. 2023 Nov; 110(11):1983-1985. Doi: 10.1016/j.ajhg.2023.10.003 (*inCites*, *JCR* 2021)
- 13) Cosi I, Moccia A, Pescucci C, Munagala U, Di Giorgio S, Sineo I, Conticello SG, **Notaro R**, De Angioletti M. Identification and characterization of novel ETV4 splice variants in prostate cancer. *Scientific Reports*. 2023 Mar 31;13(1):5267. doi: 10.1038/s41598-023-29484-1. IF: (*inCites*, *JCR* 2021)
- 14) Sica M, Barone F, Nannelli C, Ricci P, Marano L, De Angioletti M, Di Bona E, Risitano AM, **Notaro R**. The long-acting anti-C5 ravulizumab results in C3 binding to PNH red cells similar to its parental molecule eculizumab. *British Journal of Haematology*. 2023 Apr; 201(1):e1-e4. DOI: 10.1111/bjh.18662. IF: 5.518 (*inCites*, *JCR* 2019)
- 15) Girmenia C, Barcellini W, Bianchi P, Di Bona E, Iori AP, **Notaro R**, Sica S, Zanella A, De Vivo A, Barosi G, Risitano AM. Management of infection in PNH patients treated with eculizumab or other complement inhibitors: Unmet clinical needs. *Blood Reviews*. 2023 Mar; 58:101013. DOI: 10.1016/j.blre.2022.101013. Epub Sep 6 2022. IF: 10.626 (*inCites*, *JCR* 2021)
- 16) **Notaro R**, Luzzatto L. Breakthrough Hemolysis in PNH with Proximal or Terminal Complement Inhibition. *New England Journal of Medicine*. 2022 Jul 14;387(2):160-166. DOI: 10.1056/NEJMra2201664. IF: 74.699 (*inCites*, *JCR* 2019)
- 17) Kulasekararaj AG, Griffin M, Langemeijer S, Usuki K, Kulagin A, Ogawa M, Yu J, Mujeebuddin A, Nishimura JI, Lee JW, Peffault de Latour R, 301/302 Study Group (...**Notaro R**...). Long-term safety and efficacy of ravulizumab in patients with paroxysmal nocturnal hemoglobinuria: 2-year results from two pivotal phase 3 studies. *European Journal of Haematology*. 2022;109:205-214. DOI: 10.1111/ejh.13783. PMID: 35502600.
- 18) Kulasekararaj AG, Risitano AM, Maciejewski JP, **Notaro R**, Browett P, Lee JW, Huang M, Geffner M, Brodsky R. Phase 2 study of danicopan in patients with paroxysmal nocturnal hemoglobinuria with an inadequate response to eculizumab. *Blood*. 2021 Nov 18;138(20):1928-1938. DOI: 10.1182/blood.2021011388. IF: 17.543 (*inCites*, *JCR* 2019).
- 19) Debureaux PE, Kulasekararaj AG, Cacace F, Silva BGP, Calado RT, Barone F, Sicre de Fontbrune F, Prata PH, Soret J, Sica M, **Notaro R**, Scheinberg P, Mallikarjuna V, Gandhi S, Large J, Risitano AM, Peffault de Latour R, Frieri C; Severe Aplastic Anemia Working Party of the European Group for Bone Marrow Transplantation. Categorizing hematological response to eculizumab in paroxysmal nocturnal hemoglobinuria: a multicenter real-life study. *Bone Marrow Transplantation*. 2021 Oct;56(10):2600-2602.. doi: 10.1038/s41409-021-01372-0. IF: 4.725 (*inCites*, *JCR* 2019).
- 20) Luzzatto L, Risitano AM, **Notaro R**. Mutant UBA1 and Severe Adult-Onset Autoinflammatory Disease. *New England Journal of Medicine*. 2021 Jun 3;384(22):2164. DOI: 10.1056/NEJMc2102124. IF: 74.699 (*inCites*, *JCR* 2019).
- 21) Barcellini W, Fattizzo B, Giannotta JA, Quattrocchi L, Aydin S, Barone F, Carbone C, Pomponi F, Metafuni E, Beggato E, Sica S, Di Bona E, Lanza F, **Notaro R**, Iori AP. COVID-19 in patients with paroxysmal nocturnal haemoglobinuria: an Italian multicentre survey. *British Journal of Haematology*. 2021 Sept;194(5):854-856. DOI: 10.1111/bjh.17558. PMID: 34036575. IF: 5.518 (*inCites*, *JCR* 2019).
- 22) Risitano AM, Kulasekararaj AG, Lee JW, Maciejewski JP, **Notaro R**, Brodsky R, Huang M, Geffner M, Browett P. Danicopan: an oral complement factor D inhibitor for paroxysmal nocturnal hemoglobinuria. *Haematologica*. 2021 Dec 1;106(12):3188-3197. DOI: 10.3324/haematol.2020.261826. PMID: 33121236. IF: 7.116 (*inCites*, *JCR* 2019).

- 23) Sica M, Pellecchia A, De Angioletti M, Caocci G, Nannelli C, La Nasa G, Luzzatto L, **Notaro R**. Complement-mediated oxidative damage of red cells impairs response to eculizumab in a G6PD-deficient patient with PNH. **Blood**. **2020** Dec 24;136(26):3082-3085. DOI: 10.1182/blood.2020007780. IF: 17.543 (*inCites*, JCR 2019).
- 24) Cosi I, Pellecchia A, De Lorenzo E, Torre E, Sica M, Nesi G, **Notaro R**, De Angioletti M. ETV4 promotes late development of prostatic intraepithelial neoplasia and cell proliferation through direct and p53-mediated downregulation of p21. **Journal of Hematology & Oncology**. **2020**;13(1):112. DOI: 10.1186/s13045-020-00943-w. IF: 11.059 (*inCites*, JCR 2019).
- 25) Luzzatto L, Ally M, **Notaro R**. Glucose-6-Phosphate Dehydrogenase Deficiency. **Blood**. **2020**;136(11):1225-1240. DOI: 10.1182/blood.2019000944. IF: 17.543 (*inCites*, JCR 2019).
- 26) Luzzatto L, **Notaro R**. The "escape" model: a versatile mechanism for clonal expansion. **British Journal of Haematology**. **2018**;184(3):465-466. DOI: 10.1111/bjh.15111. IF: 5.518 (*inCites*, JCR 2019).
- 27) Risitano AM, Marotta S, Ricci P, Marano L, Frieri C, Cacace F, Sica M, Kulasekararaj A, Calado RT, Scheinberg P, **Notaro R***, Peffault de Latour R*. Anti-complement Treatment for Paroxysmal Nocturnal Hemoglobinuria: Time for Proximal Complement Inhibition? A Position Paper From the SAAWP of the EBMT. **Frontiers in Immunology**. **2019**;10:1157. DOI: 10.3389/fimmu.2019.01157. IF: 5.085 (*inCites*, JCR 2019). **Equal contribution*
- 28) Luzzatto L, Hyry HI, Schieppati A, Costa E, Simoens S, Schaefer F, Roos JCP, Merlini G, Kääriäinen H, Garattini S, Hollak CE, Remuzzi G; Second Workshop on Orphan Drugs participants (Barbui T, Benigni A, Costa E, Daina E, Garattini S, Gramaglia D, Hollak CEM, Hyry H, Kaarinen H, Licht C, Luzzatto L, Merlini G, **Notaro R**, Remuzzi G, Schaefer F, Schieppati A, Simoens S). Outrageous prices of orphan drugs: a call for collaboration. **Lancet**. **2018**;392(10149):791-794. DOI: 10.1016/S0140-6736(18)31069-9. IF: 60.392 (*inCites*, JCR 2019).
- 29) **Notaro R**, Sica M. C3-mediated extravascular hemolysis in PNH on eculizumab: Mechanism and clinical implications. **Seminars in Hematology**. **2018**; 55(3):130-135. DOI: 10.1053/j.seminhematol.2018.05.014. IF: 4.379 (*inCites*, JCR 2019).
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- 4) Gargiulo L, Sica M, Nannelli C, Luzzatto L, **Notaro R**. Two Distinct but Functionally Related Autoreactive T Cell Populations in Paroxysmal Nocturnal Hemoglobinuria and Idiopathic Aplastic Anemia: Glycosylphosphatidylinositol-Specific and IFN γ -Producing T Cells. **59th annual meeting of the American Society of Hematology**. Atlanta, December 9-12, 2017. *Blood* (2017) 130 (Supplement 1): 1166.
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Data aggiornamento: 24/03/2026

L'elenco dei medici e degli odontoiatri riportati in questo servizio è stato realizzato sui dati comunicati dagli Ordini Provinciali. È opportuno ricordare che ai sensi dell'art. 1 del DPR n. 221 del 5 aprile 1950 la competenza alla tenuta degli Albi dei Medici Chirurghi e degli Odontoiatri spetta ai singoli Ordini Provinciali. Si fa presente altresì che la data di iscrizione all'Ordine Provinciale è riferita alla situazione attuale e non alla data di la iscrizione.

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Principali attività e responsabilità **Attuale posizione e data assunzione: PROFESSORE ASSOCIATO EMATOLOGIA, UNITA' OPERATIVA COMPLESSA DI EMATOLOGIA e trapianto di cellule staminali**

Sintesi delle responsabilità AGGIUNTIVE ricoperte attualmente: Responsabile Programma Trapianto cellule staminali Fondazione Policlinico Universitario A. Gemelli IRCCS

Nome e indirizzo del datore di lavoro Policlinico Agostino Gemelli – Università Cattolica Sacro Cuore

Tipo di attività o settore

Istruzione e formazione

1986: Laurea in Medicina e Chirurgia summa cum laude e dignita' di stampa, presso la Facolta' di Medicina e Chirurgia della Universita' Cattolica del Sacro Cuore di Roma discutendo la tesi " Modificazioni emocoagulative e fibrinolitiche nella sclerodermia"

1987-1988: ha prestato servizio presso l'unita' di Trapianto di midollo osseo presso il Fred Hutchinson Cancer Research Center di Seattle, WA-USA

1990: Diploma di Dottorato di Ricerca in Oncologia Integrata presso la medesima Universita' con la presentazione della tesi finale intitolata " Il trapianto di cellule staminali nelle neoplasie oncoematologiche"

1992: Diploma di Specializzazione in Ematologia con il massimo dei voti e lode presso la Facolta' di Medicina e Chirurgia dell'Universita' Cattolica del Sacro Cuore di Roma con la tesi " L'associazione busulfano-ciclofosfamide nel trapianto di midollo osseo: valutazione della tossicita' correlata al trattamento e influenza della diversa di cellule staminali nella ripresa emopoietica post-trapianto"

1992: ha prestato servizio in qualita' di Medico Interno Universitario con compiti assistenziali dal Gennaio 1992 al maggio 1998 presso la Divisione di Ematologia - Istituto di Semeiotica Medica dell'Universita' Cattolica del Sacro Cuore - Policlinico Agostino Gemelli di Roma

1998: inquadrata nel ruolo di ricercatore universitario della Facolta' di Medicina e Chirurgia "A. Gemelli" dell'Universita' Cattolica del Sacro Cuore per il gruppo di discipline F07A Medicina interna con successiva afferenza al gruppo di discipline F07G Ematologia con decorrenza 1.11.1999

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Titolo della qualifica rilasciata

Principali tematiche/competenze professionali possedute

Nome e tipo d'organizzazione erogatrice dell'istruzione e formazione

Capacità e competenze personali

Madrelingua(e) **italiano**

Altra(e) lingua(e) **inglese**

Autovalutazione

Livello europeo (*)

Lingua

Lingua

Comprensione				Parlato				Scritto	
Ascolto		Lettura		Interazione orale		Produzione orale			
C1		C1		C1		C1		C1	

Ottima conoscenza dei programmi per il computer Microsoft Office Word e PowerPoint Buona conoscenza del programma per il computer Microsoft Office Excel Sufficiente conoscenza del programma per il computer Microsoft Office Access

Autrice di 450 pubblicazioni H-index Scopus 49/Google Scholar 40

Partecipazione in trials clinici; in possesso di certificazione GCP

Autorizzo il trattamento dei miei dati personali ai sensi del Decreto Legislativo 30 giugno 2003, n. 196 "Codice in materia di protezione dei dati personali (facoltativo)".

Firma



Roma , 21 gennaio 2025

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