

Giornate **AIEOP**

RIMINI

Hotel Savoia

13-14 aprile 2026

Patologie del Globulo Rosso

Raffaella Colombatti

Università degli Studi di Padova

Disclosures of Name Surname

Company name	Research support	Employee	Consultant	Stockholder	Speakers bureau	Advisory board	Other
Vertex	x		x			x	
Theravia			x				
Agios	x		x				
Pfizer			x			x	
NovoNordisk			x			x	

Coordinatore: R. Colombatti (Padova)

Membri Effettivi: S. Perrotta (Napoli), G. Russo (Catania), P. Corti (Monza) G. Palazzi (Modena), P. Bianchi (Milano), E. Bertoni (Brescia)

Consulenti: L. Notarangelo (Brescia), MP.Boaro (Padova), D. Cuzzubbo (Catania), M. Casale (Napoli)

Gruppo Allargato: >50

- Aggiornamenti Attività Internazionali, Salute Pubblica e Scenario Terapeutico
- Aggiornamento studi in corso
- Pubblicazioni varie

PROGRAMMA

- Drepanocitosi: 10 anni di screening a Modena e novità legislative per lo screening antenatale (G.Palazzi)
- Drepanocitosi: Standardizzazione a livello Europeo delle valutazioni della Qualità di Vita attualmente in corso (G.Palazzi)
- Aggiornamento Progetto EU_DGSantè Critical Appraisal of SCD Guidelines; presentazione opportunità per EHA Guidelines (G.Russo)
- Aggiornamento e Discussione Studi proposti/in corso:
 - o Sferocitosi: studio retrospettivo (M. Marinoni-C.Piccolo)
 - o SCD, studio prospettico talasso-drepanocitosi "mild" (S-beta-tal) (E.Bertoni)
 - o Proposta di studio nazionale sui Disturbi Respiratori del Sonno e Asma nei pazienti pediatrici con Drepanocitosi (Prof.ssa Nozetti/Dott.ssa Marinoni)
 - o Studio DHTR (P.Corti)
- Studio Parvovirus B19 nelle anemie emolitiche: presentazione risultati finali (MP Boaro, G Del Borrello)
- RADEEP-Rare Anemia Disorders Epidemiological Platform: aggiornamento, analisi dati e prospettive (R.Colombatti, G.Russo)
- Progetti di Intelligenza Artificiale nelle anemie rare: TCD e machine learning (V.Voj), Infarti Cerebrali Silenti e Deep Learning (R.Colombatti)
- Studio Aplenia nelle Anemie: Aggiornamento pubblicazioni, analisi e prospettive di ricerche future (M.Casale)
- Talassemie: Analisi dei dati raccolti in RADEEP sull'accumulo di ferro – standardizzazione dell'inserimento e del follow-up (M.Casale)
- Aggiornamenti raccolta dati e analisi preliminare studio "diagnostica" (M.Casale)
- Trial Clinici in Corso (discussione vari)
- Varie ed eventuali (HU e vaccini);

AIEOP SCD GUIDELINES del 2023 – Tradotte in Inglese



Associazione Italiana Ematologia Oncologia Pediatrica

Gruppo di Lavoro “Patologia del globulo rosso”
Coordinatori: Silverio Perrotta - Giovanna Russo

LINEE-GUIDA PER LA GESTIONE DELLA MALATTIA DREPANOCITICA IN ETA' PEDIATRICA IN ITALIA

G. Russo e D.Cuzzubbo (CT)
M.Casale (NA)
R.Colombatti (PD)

- Pubblicazione sul sito eurobloodnet.eu
- Critical appraisal of EU guidelines



Associazione Italiana Ematologia Oncologia Pediatrica

Gruppo di Lavoro "Patologia del globulo rosso"
Coordinatori: Silverio Perrotta - Giovanna Russo

LINEE-GUIDA PER LA GESTIONE DELLA
MALATTIA DREPANOCITICA IN ETA'
PEDIATRICA IN ITALIA

 SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA
Azienda Ospedaliero - Universitaria di Bologna
IRCCS Istituto di Ricovero e Cura a Carattere Scientifico

Dipartimento per la gestione integrata del rischio infettivo
Malattie infettive UOC



POLICLINICO DI
SANT'ORSOLA



ALMA MATER STUDIORUM
UNIVERSITÀ DI BOLOGNA

20/01/2026

Gent. mi Colleghi,
vi ringraziamo per avere richiesto il parere del Vax-consilium.
Il quesito che ci viene posto riguarda la sussistenza di controindicazioni ed il rapporto rischio-beneficio della somministrazione delle vaccinazioni vive attenuate in minori affetti da Drepanocitosi in trattamento con Idrossiurea.

Raccomandazioni del Gruppo tecnico "Talassemie ed Emoglobinopatie" della Regione Emilia Romagna sull'uso di vaccini vivi attenuati per MPRV in bambini affetti da drepanocitosi

Angelica Barone¹, Patrizia Albertini², Monica Benni³, Patrizia Bernuzzi⁴, Rino Biguzzi², Costanza Bosi⁴, Simona Bulgarelli², Benedetta Cambò¹, Monica Caruso², Erminia Di Bartolomeo⁵, Elena Facchini³, Francesca Ferrara⁶, Beatrice Filippini², Elena Follini⁴, Annalisa Gabriele², Liliya Kodzhebash⁵, Nesrine Gamal Mohamed Abdelall⁵, Filomena Longo⁷, Cinzia Moretti², Giovanni Palazzi⁶, Micol Quaresima⁵, Caterina Radice², Francesco Romeo⁴, Maria Beatrice Rondinelli³, Daniele Vallisa⁴, Donatella Venturelli⁶.

Gruppo tecnico "Talassemie ed Emoglobinopatie" della Regione Emilia Romagna.

¹Parma, ²Romagna, ³Bologna, ⁴Piacenza, ⁵Reggio nell'Emilia, ⁶Modena, ⁷Ferrara

2026 Sicurezza vaccini vivi in lattanti con SCD che assumono Idrossiurea

NUOVE TERAPIE, SCD

<12 years

- HU precoce in genotipi severi con ottimizzazione dose
- Trasfusioni RBC
- HSCT
- **Upcoming clinical trials in 1 year (etavopivat, mitapivat, other?)**

≥12 years

- Ottimizzazione HU, Trasfusioni RBC, HSCT
- **Gene therapy**
- **Etavopivat, Trial Hibiscus 2**
- **Crovalimab, Crosswalk 2**
- **Rizalbrutinib (>10 aa)**
- **Upcoming clinical Trials (Pociredir, Tebapivat, Osivelotor...)**

NUOVE TERAPIE, Talassemia

- Trasfusioni RBC, chelanti
- Luspatarcept

- Gene Therapy
- Etavopivat (Trial) >12
- Upcoming Mitapivat 1-18 anni

“A retrospective/prospective, multicenter European Epidemiological Platform for patients diagnosed with Rare Anemia Disorders (RADs) with clinical significance, in concrete Sickle cell disease and Thalassaemia disorders, and other rare defects of the red blood cell and erythropoiesis”

RADeep, 1° National Meeting
11 marzo 2026, Milano



European
Reference
Network

for rare or low prevalence
complex diseases

Network
Hematological
Diseases (ERN EuroBloodNet)





+ 6456

patients



10

countries

16

diseases

+ undiagnosed cases

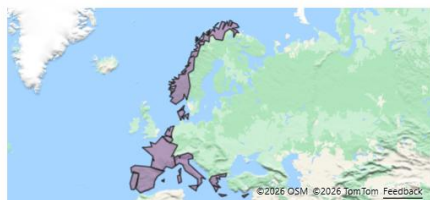
Last data update: 27/02/2026 12:42:08

RADeep Epidemiological Data

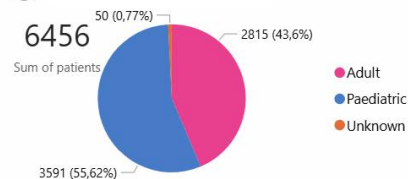


Explore the global distribution and demographics of RAD patients registered in the platform by country, disease, and age group.

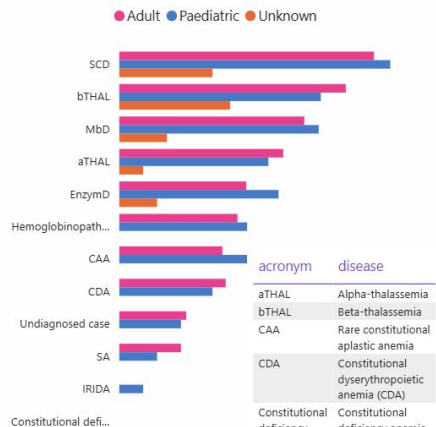
Country Distribution - Total Patients



Age Group Distribution



RAD Patients by Disease and Age Group



10 stati europei con inserimento dati:

- Italia: 1808
- Belgio: 1161
- Spagna: 1155
- Francia: 917
- Olanda: 518
- Cipro: 406
- Grecia: 248
- Danimarca: 128
- Norvegia: 85
- Portogallo: 32

RADeep Network - Italy

Italy – HCP in RADeep

Ancona - Azienda Ospedaliero-Universitaria-Ospedali Riuniti Ancona	Milano - Ospedale San Raffaele	Pisa - Azienda Ospedaliera Universitaria Pisana
Bari - A.O.U. Policlinico Dipartimento di Pediatria	Modena - AOU Policlinico di Modena S.C. di Medicina Interna	Rimini - Azienda USL Romagna
Bari - Università di Bari	Modena - Azienda Ospedaliero Universitaria Policlinico di Modena	Roma - Fondazione Policlinico Universitario Agostino Gemelli- IRCCS
Bergamo - A.O. Papa Giovanni XXIII	Monza - IRCCS San Gerardo dei Tintori SSD Malattie Rare	Roma - Policlinico Umberto I Università "La Sapienza"
Bologna - Azienda Ospedaliero-Universitaria di Bologna - IRCCS Policlinico di S.Orsola	Monza - IRCCS San Gerardo dei Tintori, Pediatria	San Giovanni Rotondo - IRCCS Ospedale "Casa Sollievo della Sofferenza"
Bolzano - Ospedale Centrale di Bolzano	Napoli - Università della Campania "L. Vanvitelli"	Torino - Centro Regionale Unico Piemonte e Valle d'Aosta Presidio Infantile Regina Margherita
Brescia - ASST Spedali Civili di Brescia	Padova - Azienda Ospedale - Università di Padova Clinica Medica 1	Trento - Azienda Provinciale per i Servizi Sanitari
Catanzaro - Azienda Ospedaliera "Pugliese-Ciaccio" di Catanzaro	Padova - Azienda Ospedale Università Padova	Trieste - IRCCS materno infantile Burlo Garofolo
Ferrara (Cona) - Azienda Ospedaliero Universitaria Sant'Anna	Parma - Azienda Ospedaliero-Universitaria di Parma	Udine - Azienda Sanitaria Universitaria Friuli Centrale
Firenze - Azienda Ospedaliero-Universitaria Anna Meyer	Pavia - Fondazione IRCCS Policlinico San Matteo	Varese - Azienda Ospedale - Università Insubria ASST SETTELAGHI
Genova - Ente Ospedaliero Ospedali Galliera	Perugia - Azienda ospedaliera di Perugia	Verona - Azienda Ospedaliera Universitaria Integrata di Verona - Ospedale della Donna e del Bambino
Genova - IRCCS "Istituto Giannina Gaslini"	Pescara - Presidio Ospedaliero Spirito Santo-Ematologia Clinica	

Centri attivi pediatrici: 34

Centri attivi adulti: 5

Centri di prossima attivazione: 2



European Reference Network

for rare or low prevalence complex diseases

Network Hematological Diseases (ERN EuroBloodNet)

Italy - Diagnosis	Total Patients
Alpha-thalassemia	18
Beta-thalassemia	412
Constitutional anemia due to iron metabolism disorder	1
Constitutional deficiency anemia	1
Constitutional dyserythropoietic anemia (CDA)	27
Hemoglobin C disease	6
Hemoglobin E disease	2
Hereditary methemoglobinemia	3
Rare constitutional aplastic anemia	11
Rare constitutional hemolytic anemia due to a red cell membrane anomaly	464
Rare constitutional hemolytic anemia due to an enzyme disorder	13
Sickle cell disease and related diseases	841
Sideroblastic anemia	1
Undiagnosed case	1
Unstable hemoglobin disease	6
N/A	1
Totale	1808

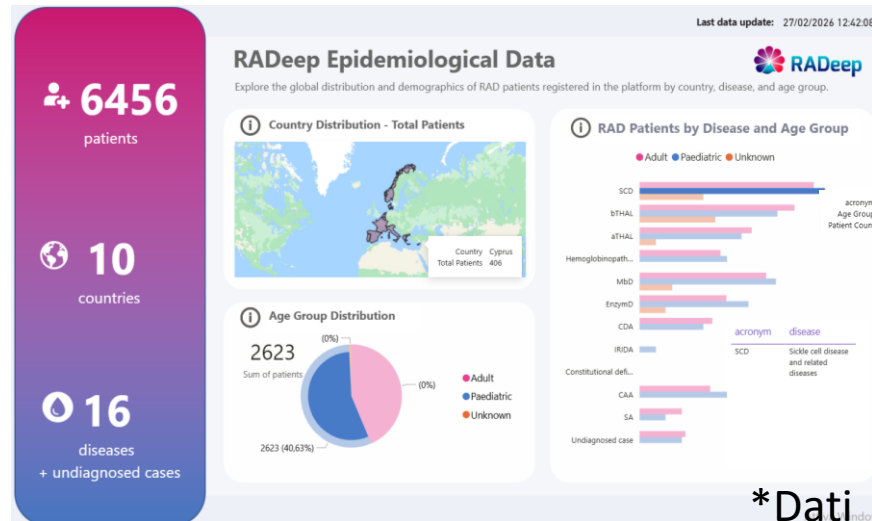
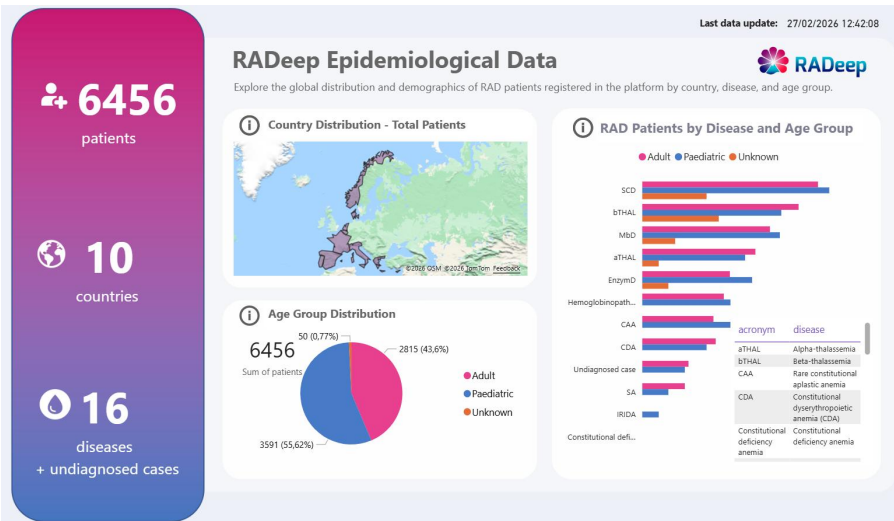
1808



- ☑ visualizations
 - 1) RADeep Epidemiological Data (PowerBI) ←
 - 2) RADeep Descriptive Tables (Shiny)
 - 3) RADeep Coverage Report (Shiny)
 - 4) RADeep Completeness Report (Shiny)
- ☑ visualizations_credentials
 - 1) ██████████ - RADeep Dashboards Credentials

Visualizzazione Reportistica

Tool 1: RADeep Epidemiological data



*Dati



Visualizzazione Reportistica Tool 2: RADeep Descriptive Tables



RADeep Descriptive Tables

Interactive Patient Registry Analytics Dashboard

Navigation

Public Dashboard

Tables per Episode

Tables per Patient

About

Data Filters

Country

Italy

Healthcare Provider

Patient Episode Information

This section provides detailed information about patient visits across the RADeep registry, allowing you to track patient retention and follow-up completion rates.

- Baseline** : Initial patient assessment with complete medical history and examination.
- Follow-up 1-5** : Scheduled follow-up visits occurring at regular intervals to monitor disease progression and treatment response.
- Follow-up 6+** : Long-term monitoring visits for patients with extended registry participation.

These tables help identify areas where patient follow-up might need improvement or where successful retention strategies could be shared.

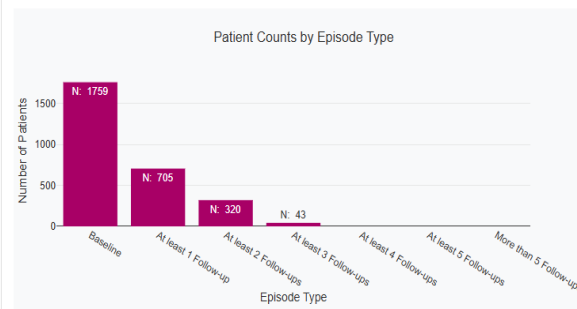
Patient Episodes

Search:

Episode Type	Number of Patients
Baseline	1759
At least 1 Follow-up	705
At least 2 Follow-ups	320
At least 3 Follow-ups	43
At least 4 Follow-ups	0
At least 5 Follow-ups	0
More than 5 Follow-ups	0

*Tabella con possibile copia/incolla su Excel

Patient Follow-up Visualization



*Grafico a barre scaricabile in png

*Dati italiani



Visualizzazione Reportistica Tool 2: RADeep Descriptive Tables

Patient Episodes by HCP

Show 15 entries

Search:

Country	Healthcare Provider	Baseline	Follow-up 1	Follow-up 2	Follow-up 3	Follow-up 4	Follow-up 5	Follow-up 6+	Total Patients
Italy	Ancona - Azienda Ospedaliero-Universitaria-Ospedali Riuniti Ancona	54	36	30	1	0	0	0	54
Italy	Bari - Università di Bari	10	8	6	0	0	0	0	10
Italy	Bergamo - A.O. Papa Giovanni XXIII	57	46	26	0	0	0	0	57
Italy	Bologna - Azienda Ospedaliero-Universitaria di Bologna - IRCCS Policlinico di S.Orsola	4	0	0	0	0	0	0	4
Italy	Bolzano - Ospedale Centrale di Bolzano	22	20	16	0	0	0	0	22
Italy	Brescia - ASST Spedali Civili di Brescia	55	52	30	0	0	0	0	55
Italy	Catania - Azienda Ospedaliero-Universitaria	0	0	0	0	0	0	0	0

Inserimenti totali per HCP

Inserimenti totali per patologia

Patient Episodes by Diagnosis

Show 15 entries

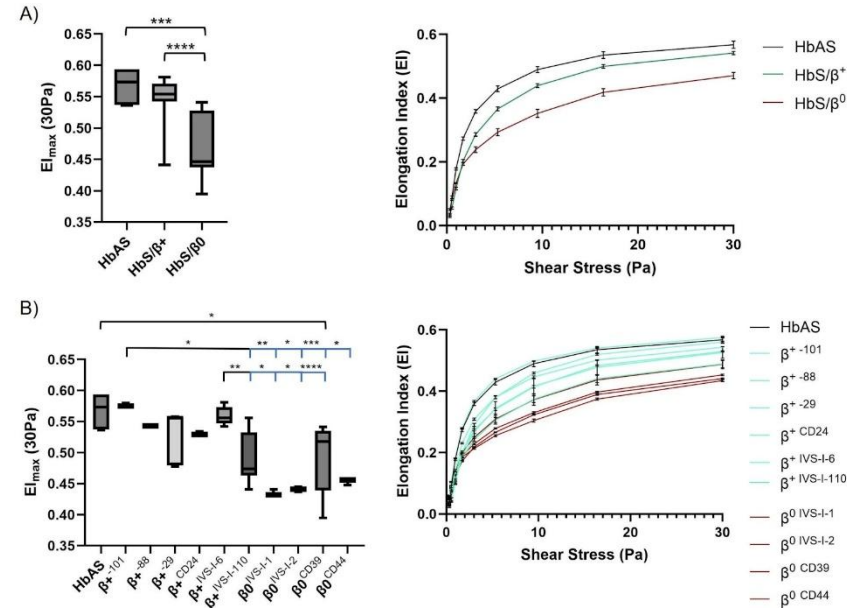
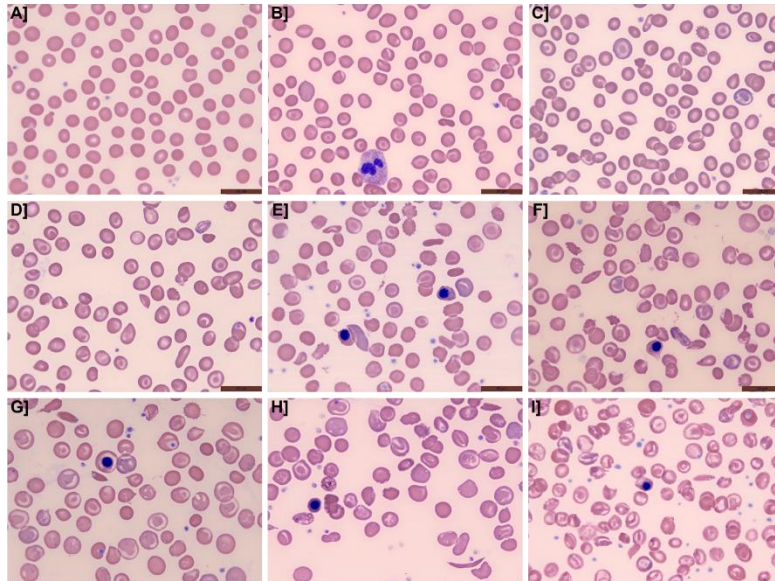
Search:

Country	Diagnosis	Baseline	Follow-up 1	Follow-up 2	Follow-up 3	Follow-up 4	Follow-up 5	Follow-up 6+	Total Patients
Italy	Sickle cell disease and related diseases	799	447	180	19	0	0	0	799
Italy	Rare constitutional hemolytic anemia due to a red cell membrane anomaly	462	121	41	1	0	0	0	462
Italy	Beta-thalassemia	386	113	79	23	0	0	0	386
Italy	Constitutional dyserythropoietic anemia (CDA)	27	4	4	0	0	0	0	27
Italy	Alpha-thalassemia	17	3	1	0	0	0	0	17
Italy	Rare constitutional hemolytic anemia due to an enzyme disorder	11	7	6	0	0	0	0	11
Italy	Rare constitutional aplastic anemia	9	4	4	0	0	0	0	9
Italy	Hemoglobin C disease	6	1	1	0	0	0	0	6
Italy	Unstable hemoglobin disease	6	3	3	0	0	0	0	6
Italy	Hereditary methemoglobinemia	3	1	1	0	0	0	0	3
Italy	Hemoglobin E disease	2	0	0	0	0	0	0	2

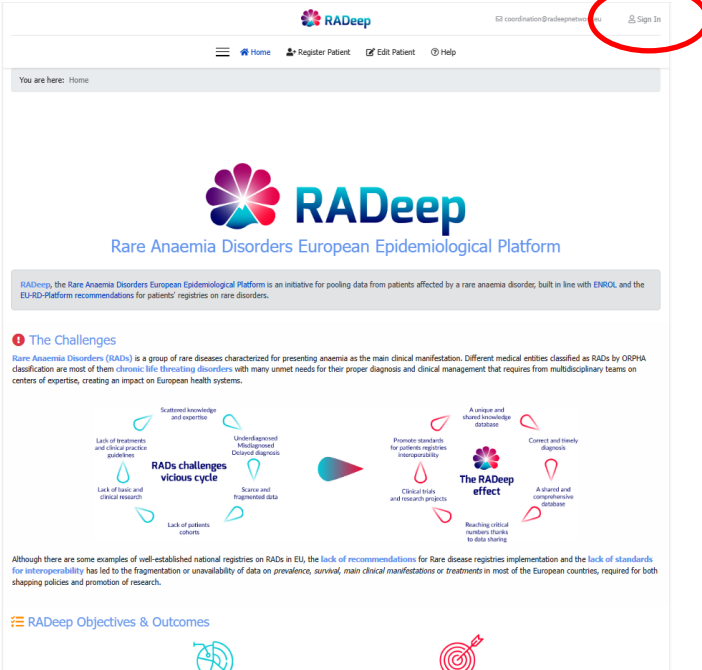
*Tabelle con possibile copia/incolla su Excel

*Dati italiani

Rethinking Sickle β^+ Thalassemia severity through an integrated genetic, rheological, morphological and clinical lens



Monitoraggio del sovraccarico di ferro nei pazienti pediatrici affetti da emoglobinopatia ed altre anemie rare (M.Casale, NA)



The screenshot shows the RADeep website interface. At the top right, the 'Sign In' button is circled in red. The navigation menu includes 'Home', 'Register Patient', 'Edit Patient', and 'Help'. The main content area features the RADeep logo and the text 'Rare Anaemia Disorders European Epidemiological Platform'. Below this, there is a paragraph describing the platform as an initiative for pooling data from patients affected by a rare anaemia disorder. The 'The Challenges' section follows, explaining that Rare Anaemia Disorders (RADs) are a group of rare diseases characterized by presenting anaemia as the main clinical manifestation. It then presents two diagrams: 'RADs challenges vicious cycle' and 'The RADeep effect'. The 'RADs challenges vicious cycle' diagram shows a cycle of interconnected challenges: 'Scattered knowledge and expertise', 'Lack of treatments and clinical practice guidelines', 'Lack of basic and clinical research', 'Lack of patients cohorts', 'Scarcy and fragmented data', and 'Underreported Misdiagnosed Delayed diagnosis'. The 'The RADeep effect' diagram shows a cycle of interconnected benefits: 'A unique and shared knowledge database', 'Correct and timely diagnosis', 'A shared and comprehensive database', 'Reaching critical numbers thanks to data sharing', 'Clinical trials and research projects', and 'Promote standards for patients registries interoperability'. At the bottom, there is a section for 'RADeep Objectives & Outcomes' with a target icon.

Sign In

Home Register Patient Edit Patient Help

You are here: Home

RADeep

Rare Anaemia Disorders European Epidemiological Platform

RADeep, the Rare Anaemia Disorders European Epidemiological Platform is an initiative for pooling data from patients affected by a rare anaemia disorder; built in line with ENROL and the EU-RD-Platform recommendations for patients' registries on rare disorders.

The Challenges

Rare Anaemia Disorders (RADs) is a group of rare diseases characterized for presenting anaemia as the main clinical manifestation. Different medical entities classified as RADs by ORPHA classification are most of them chronic, life threatening disorders with many unmet needs for their proper diagnosis and clinical management that requires from multidisciplinary teams on centers of expertise, creating an impact on European health systems.

RADs challenges vicious cycle

- Scattered knowledge and expertise
- Underreported Misdiagnosed Delayed diagnosis
- Scarcy and fragmented data
- Lack of patients cohorts
- Lack of basic and clinical research
- Lack of treatments and clinical practice guidelines

The RADeep effect

- A unique and shared knowledge database
- Correct and timely diagnosis
- A shared and comprehensive database
- Reaching critical numbers thanks to data sharing
- Clinical trials and research projects
- Promote standards for patients registries interoperability

Although there are some examples of well-established national registries on RADs in EU, the **lack of recommendations** for Rare disease registries implementation and the **lack of standards for interoperability** has led to the fragmentation or unavailability of data on prevalence, survival, main clinical manifestations or treatments in most of the European countries, required for both shapping policies and promotion of research.

RADeep Objectives & Outcomes

PARVOVIRUS B19 infection in Congenital Anemias, referenti MP.Boaro (PD), G.Del Borrello (TO)

- Abstract su dati preliminari EHA 2025, Milano
- Analisi dati finali conclusa
- Manuscript in preparazione

EHA2025 Congress

June 12-15 | Milan, Italy

INTRODUCTION

Parvovirus B19 infection is a significant challenge for patients with congenital anemias.

The recent worldwide 2023-2024 Parvovirus B19 epidemic has been particularly severe in children and reports of unprecedented clinical complexity in individuals with congenital anemias have been reported, with acute aplastic crises and leading to potentially life-threatening complications.

AIM

The objective of this study was to assess the clinical impact and outcome of the Parvovirus B19 infection on children and young adults with red blood cell disorders followed in Italian Association of Pediatric Hematology and Oncology (AIEOP) Centres and enrolled in the Rare Anemia Disorders European Epidemiological Platform (RADEEP), the ERN EuroBloodNet promoted registry for Rare Anemias.

METHODS

Data of patients affected by Parvovirus B19 infection between 1st October 2023 and 31st October 2024 were retrieved from medical records.

Parvovirus B19 was detected by serological tests or molecular biology.

Descriptive statistics were performed, including the calculation of frequencies and percentages for categorical variables and measures of central tendency and dispersion for continuous variables.

Epidemiology And Severity Of Parvovirus B19 Infection In Red Blood Cell Disorders During The Epidemic Season 2023-2024: A Nationwide Report from Italian AIEOP Centres

RESULTS

335 patients with symptomatic Parvovirus 19 infection were hospitalized in the 25 participating Centres (mean length of stay 4.4 to 6.4 days); 46.6% had SCD, 44.3% HS, 4.9% thalassemia, 1% enzymopathies and 3.2% other rare anemias (Figure 1, A).

Mean age at admission was 8 yo for SCD, 8.9 yo for thalassemia, 7.5 yo for HS.

Mean hemoglobin and mean reticulocytes at steady state were significantly higher for HS than SCD and thalassemia. Among SCD patients, 68.8% was on hydroxyurea, at mean dosage of 21.2 mg/kg/die. Clinical manifestations included fever (67% of SCD, 66% of thalassemia and 91% of HS), fatigue (51% of SCD, 73% of thalassemia and 83% of HS), followed by abdominal pain and arthritis.

Some patients experienced severe complications: acute kidney injury (0.7% of SCD and HS), myocarditis (0.7% of SCD and 1.4% of HS) and hemophagocytic lymphohistiocytosis (2.9% of SCD). Among SCD, 40% had VOC, 10.9% ACS and 0.7% stroke. Severe Anemia and reticulocytopenia were observed in all the patients; subjects with HS had a more drastic decrease in hemoglobin compared to SCD, Thalassemia, or other conditions (p-value: <0.0001) (Figure 1, B). Treatment strategies included iv immunoglobulin (7.7% of SCD, 6.7% of thalassemia and 6.6% of HS), steroid therapy, administered to 3.5% of SCD, 6.7% of thalassemia and 2.9% of HS. Erythropoietin was administered to 3.5% of SCD and 3.7% of HS. 266 patients received red blood cells transfusions, 8.4% of SCD needed exchange transfusion (Figure 1, C-D).

Complete blood count was restored at steady state values for all the patients, 14 patients needed ICU admission; one of them died from multiorgan failure during persistent severe anemia.

CONCLUSIONS

After the COVID-19 pandemic, many countries saw a rise in infectious diseases. Current data suggest that the temporarily reduced pathogen exposure, created an 'immunity gap'. Once lifted, this gap may have contributed to larger outbreaks and more severe infections. The ongoing Parvovirus B19 outbreak in Europe, appears to be causing more severe cases and our data support this in patients affected by red blood cell disorders. The current data on Parvovirus B19 infection from AIEOP Centres, show an important number of hospitalizations in this cohort of rare diseases, with important clinical implications.

REFERENCES

1. ...
2. ...
3. ...
4. ...
5. ...
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8. ...
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10. ...

ACKNOWLEDGEMENT

This project is carried out in the framework of the European Hematology Network on Rare Anemias (EHNR) and the Italian Association of Pediatric Hematology and Oncology (AIEOP) Centres and enrolled in the Rare Anemia Disorders European Epidemiological Platform (RADEEP), the ERN EuroBloodNet promoted registry for Rare Anemias.

CONTACT INFORMATION

Maria Boaro: ...
Giovanni Del Borrello: ...

Figure 1. Color of patients included in the study (A), % of no reduction from basal state of infection (B), number of total transfusions administered per patient (C) and total amount of transfused RBCs per patient (D). One-way ANOVA for multiple comparison: *p<0.05, **p<0.01, ***p<0.001.

Giornate AIEOP

Casistica
30 Centri AIEOP
2023-2024

333 infezioni in
SCD-HS-Thal/3129
pazienti (10,6%)

Patologia	(se altro)	N°	Freq.
SCD		161	48,4%
Thalassemia		20	6%
HS		152	45,6%
Enzimopatia		3	0,9%
Altro	Anemia Sideropenica	2	
	Anemia microcitica	1	
	Blackfan-Diamond	1	
	Stomatocitosi	2	
	Ovalocitosi	1	
	Sensibilizzazione anti-B	1	
	Aplasia (Sospetto DBA)	1	
	Sospetto membranopatia	1	
	Non specificato	2	
	Totale "Altro"		12
TOTALE:		348	100,0%

Nord	Centro	Sud
61,9%	18,3%	19,8%



Figure1: Geographical distribution of participating centres across Italy and Parvovirus B19 infection rates. Pin sizes and colour intensities are proportional to the empirical Bayes-adjusted infection rates, expressed as percentage of patients with HDs infected with B19V followed at each centre and weighted by total number of HD patients followed through centres to reduce instability due to small sample sizes (map created with Datawrapper).

Infection rates

SCD	11,7% (161 out of 1380)
Sferocitosi	17,5% (152 out of 869)
Talassemia	2,3% (20 out of 880)

Mean ages:

SCD 7.9 yrs
Thalassemia 10 yrs
HS 7.6 yrs
(p-value: 0.842)

p-value: <0.0001

Diagnosi nota prima dell'infezione?

No differences across categories (p-value: 0.868)

45/333 non note (13,5%)

Di cui:

- **20** Sferocitosi
- **22** SCD (circa metà HbSC ed HbSS e metà «SCD» con genotipo non specificato)
- **3** Talassemie

SCD genotype analysis:

HbSC genotype higher rate of previously undiagnosed cases compared to others (HbSC 31.8% vs HbSS 10.0% and HbS/ β -thal 5.3%; p-value: 0.0196)

Trattamenti

Therapy	Hematological Diseases			p-value
	Sickle Cell Disease	Spherocytosis	Thalassemia	
IVIg (n/N, %)	11/161, 6.8%	10/152, 6.6%	1/20, 5.0%	0.927
IVIg Dosage (mean, mg/Kg)	1660.0	864.6	2000.0	0.024*
EPO (n/N, %)	4/161, 2.5%	6/152, 3.9%	0/20, 0.0%	0.854
EPO Dosage (mean, U/week)	21400	16000	NA	0.524
Antibiotics (n/N, %)	120/161, 74.5%	63/152, 41.4%	8/20, 40.0%	<0.0001****
Corticosteroids (n/N, %)	7/161, 4.3%	4/152, 2.6%	2/20, 10.0%	0.037*
Transfusions (n/N, %)	134/161, 83.2%	145/152, 95.4%	17/20, 85.0%	0.0024**
N°Transfusions/patient (mean)	1.6	1.4	1.9	0.0085**
Transfused RBCs (mean, mL/Kg)	14.3	19.9	16.3	<0.0001****

Outcomes clinici e di laboratorio

Ricovero in TIPED?

- SCD: 6,2% (9/154)
- Talassemia: 0%
- HS: 2,1% (3/145)
- Enzimopatia: 33,3% (1/3)
- Altro: 8,3% (1/12)

Esito (vivo)?

- SCD: 99,4% (**1 deceduto**)
- Talassemia: 100%
- HS: 100%
- Enzimopatia: 100%
- Altro: 100%

Qualità di vita nella SCD,
referenti G.Palazzi, R.Colombatti

Sferocitosi nel neonato,
referenti C.Piccolo, M.Marinoni (VA)

Raccolta casistica di DHTR in SCD,
referenti P.Corti, G.Ferrari (MZ)

Studio sull'asma e disturbi del sonno nella SCD,
Referente M.Marinoni (VA)



Gruppo di Lavoro Patologie del Globulo Rosso

Sezione 1 di 22

Survey: nuove diagnosi di emoglobinopatia 2024/2025

Gentile Collega,

il GdL Patologia del Globulo Rosso ha tra i suoi obiettivi prioritari anche quello di evidenziare eventuali criticità nella gestione dei bambini affetti da emoglobinopatia in Italia e trovare soluzioni compatibili con il nostro sistema organizzativo nazionale.

Pertanto, ti chiediamo di rispondere a questa breve survey, focalizzata sui bambini **PRESI IN CARICO PER LA PRIMA VOLTA PRESSO I CENTRI DI CURA NEGLI ANNI 2024 e 2025**.

Considera solo pazienti di nuova diagnosi e non pazienti già diagnosticati e trasferiti al tuo centro nel periodo indicato.

In questo modo sarà possibile valutare età media e modalità di riferimento dei bambini con emoglobinopatia, al fine di pianificare azioni di miglioramento.

Il contributo di ognuno è fondamentale.

Grazie



AYAs with chronic
Hematological Disorders

Position paper
European Survey
on AYA services



Inter ERN Transition Group

Framework for
chronic rare
disorders

Underlying disease is the main risk factor in post-splenectomy complication risk: Data from a national database

RESEARCH

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Global haematology

Incorporating national disease burden in GBD estimates of haemoglobinopathies in Italy



LETTER TO THE EDITOR

Open Access

Narratives unveil knowledge and awareness-related issue, reinforcing patients' self-identity in sickle cell disease



