



Diana Marinello

Nationality: Italian **Date of birth:** 10/04/1985 **Email:** diana.marinello@gmail.com

WORK EXPERIENCE

Network and Programme Manager ERN ReCONNET

Azienda Ospedaliero Universitaria Pisana [05/2017 – Current]

City: Pisa | Country: Italy

Coordination and management of the activities of the European Reference Network on rare and complex connective tissue and musculoskeletal diseases

Programme Manager

Azienda Ospedaliero Universitaria Pisana [02/2020 – Current]

City: Pisa | Country: Italy

Project Manager of the European Registry Infrastructure for data harmonization in rare and complex connective tissue and musculoskeletal diseases (TogethERN ReCONNET)

Language school teacher

vhs Kaufbeuren [08/2013 – 07/2015]

City: Kaufbeuren | Country: Germany

Italian language teacher for German speakers

International and European Project Manager

SIMBA OdV [10/2015 – 05/2017]

Country: Italy

Patient Advocate and Representative for Behçet's disease
Responsible of International Relations of the association

EDUCATION AND TRAINING

Political Sciences and international relations

[2023 – Current]

Master in Applied Narrative Medicine

ISTUD [09/2022]

Master in Methodologies supporting patient engagement and communication

[03/2022]

Orphanet nomenclature and Orphanet Rare Disease Ontology

Orphanet [08/2021]

Traning on ICH Good Clinical Praticc Guidelines

AVANTYO Institute of Clinical Research [03/2021]

EURORDIS Leadership School on Healthcare & Research

[11/2020]

International Summer School on Rare Disease Registries and FAIRification of Data

[08/2020]

Project Management advanced course

Stargate Consulting [07/2020]

Licence for the Morisky Widget MMAS-8 medication adherence and medication reconciliation

[05/2019]

Eurordis Summer School on medicines research and development

[05/2018]

Project Management Certificate

Italian Project Management Institute [02/2018]

Degree in Foreign languages

Roma Tre University [03/2008]

LANGUAGE SKILLS

Mother tongue(s): Italian

Other language(s): English | German | French

PUBLICATIONS

[2024]

A cost-of-illness study of Behçet syndrome in Italy

Lorenzoni V, Marinello D, Palla I, Mosca M, Turchetti G, Talarico R. A cost-of-illness study of Behçet syndrome in Italy. *Eur J Health Econ.* 2024 Apr;25(3):411-422. doi: 10.1007/s10198-023-01593-8. Epub 2023 May 22. PMID: 37212892; PMCID: PMC10973046.

[2023]

Exploring disease perception in Behçet's syndrome: combining a quantitative and a qualitative study based on a narrative medicine approach

Marinello D, Palla I, Lorenzoni V, Androozzi G, Pirri S, Ticciati S, Cannizzo S, Del Bianco A, Ferretti E, Santoni S, Turchetti G, Mosca M, Talarico R. Exploring disease perception in Behçet's syndrome: combining a quantitative and a qualitative study based on a narrative medicine approach. *Orphanet J Rare Dis.* 2023 Mar 18;18(1):58. doi: 10.1186/s13023-023-02668-8. PMID: 36934245; PMCID: PMC10024433.

[2023]

Patient Care Pathways for Pregnancy in Rare and Complex Rheumatic Diseases: Results From an International Survey

Tani C, Zucchi D, Bellis E, Birru Talabi M, Frise C, de Jesús GR, Koksvik HS, Lledó GM, Mekinian A, Marinello D, Palla I, Mehta P, Comet LS, Shaimaa S, Smeele HTW, Talarico R, Brucato A, Khamashta M, Shoenfeld Y, Tincani A, Mosca M. Patient Care Pathways for Pregnancy in Rare and Complex Rheumatic Diseases: Results From an International Survey. *J Rheumatol.* 2023 Jul;50(7):934-938. doi: 10.3899/jrheum.220773. Epub 2023 Jan 15. PMID: 36642433...

[2023]

Long-term outcomes of COVID-19 vaccination in patients with rare and complex connective tissue diseases: The ERN-ReCONNET VACCINATE study

Tani C, Cardelli C, Depascale R, Gamba A, Iaccarino L, Doria A, Bandeira M, Dinis SP, Romão VC, Gotelli E, Paolino S, Cutolo M, Di Giosaffatte N, Ferraris A, Grammatico P, Cavagna L, Codullo V, Montecuccio C, Longo V, Beretta L, Cavazzana I, Fredi M, Peretti S, Guiducci S, Matucci-Cerinic M, Bombardieri S, Burmester GR, Fonseca JE, Frank C, Galetti I, Hachulla E, Müller-Ladner U, Schneider M, Smith V, Tamirou F, Van Laar JM, Vieira A, D'Urzo R, Cannizzo S, Gaglioti A, Marinello D, Talarico R, Mosca M. Long-term outcomes of COVID-19 vaccination in patients with rare and complex connective tissue diseases: The ERN-ReCONNET VACCINATE study. *J Transl Autoimmun.* 2023 Nov 28;7:100221. doi: 10.1016/j.jtauto.2023.100221. PMID: 38162456; PMCID: PMC10755036.

[2023]

ERN ReCONNET points to consider for treating patients living with autoimmune rheumatic diseases with antiviral therapies and anti-SARS-CoV-2 antibody products

Write here the description...Talarico R, Ramirez GA, Barreira SC, Cardamone C, Triggianese P, Aguilera S, Andersen J, Avcin T, Benistan K, Bertias G, Bortoluzzi A, Bouillot C, Bulina I, Burmester GR, Callens S, Carreira PE, Cervera R, Cutolo M, Damian L, Della-Torre E, Faria R, Fonseca JE, Galetti I, Hachulla E, Iaccarino L, Jacobsen S, Khmelinskii N, Limper M, Marinello D, Meyer A, Moroncini G, Nagy G, Olesinska M, Pamfil C, Pileckyte M, Pistello M, Rednic S, Richez C, Romão VC, Schneider M, Sciascia S, Scirè CA, Simonini G, Smith V, Sulli A, Tani C, Tas SW, Tincani A, Vonk MC, Tektonidou M, Mosca M. ERN ReCONNET points to consider for treating patients living with autoimmune rheumatic diseases with antiviral therapies and anti-SARS-CoV-2 antibody products. *Clin Exp Rheumatol.* 2023 Mar;41(3):543-553. doi: 10.55563/clinexprheumatol/jpargp. Epub 2023 Mar 14. PMID: 36916322.

[2022]

Exploring patient's experience and unmet needs on pregnancy and family planning in rare and complex connective tissue diseases: a narrative medicine approach

Marinello D, Zucchi D, Palla I, Aguilera S, Galetti I, Holmner M, Sandulescu S, Scarle L, Tremarias D, Bouillot C, Cattaneo L, Gaglioti A, Ticciati S, Brucato A, Khamashta M, Shoenfeld Y, Tincani A, Talarico R, Tani C, Mosca M. Exploring patient's experience and unmet needs on pregnancy and family planning in rare and complex connective tissue diseases: a narrative medicine approach. *RMD Open.* 2022 Dec;8(2):e002643. doi: 10.1136/rmdopen-2022-002643. PMID: 36597980; PMCID: PMC9748988.

[2022]

An overlook on the current registries for rare and complex connective tissue diseases and the future scenario of TogethERN ReCONNET

Bandeira M, Di Cianni F, Marinello D, Arnaud L, Cannizzo S, Carta C, Cornet A, Barril SM, Bulina I, Ferraris A, Fonseca J, Gaglioti A, Limper M, Lorenzoni V, Majnik J, Matucci-Cerinic M, Palla I, Rednic S, Schneider M, Smith V, Sulli A, Søndergaard K, Ticciati S, Tincani A, Turchetti G, Talarico R, Cutolo M, Mosca M and Taruscio D (2022) An overlook on the current registries for rare and complex connective tissue diseases and the future scenario of TogethERN ReCONNET. *Front. Med.* 9:889997. doi: 10.3389/fmed.2022.889997

Link: <https://doi.org/10.3389/fmed.2022.889997>

[2022]

Assessing quality of life in Behçet's disease: a systematic review

Mastrolia MV, Marinello D, Di Cianni F, Talarico R, Simonini G. Assessing quality of life in Behçet's disease: a systematic review. *Clin Exp Rheumatol.* 2022 Sep;40(8):1560-1566. doi: 10.55563/clinexprheumatol/sian1b. Epub 2022 Sep 14. PMID: 36106544.

Link: <https://doi.org/10.55563/clinexprheumatol/sian1b>

[2022]

Sharing good practice in rare diseases: the experience of an innovative hybrid laboratory of narrative medicine and narrative psychology for patients and caregivers living with Behçet's disease

Marinello D, Manzo A, Palla I, Del Bianco A, Mosca M, Taruscio D, Polvani S, Talarico R. Sharing good practice in rare diseases: the experience of an innovative hybrid laboratory of narrative medicine and narrative psychology for patients and caregivers living with Behçet's disease. *Clin Exp Rheumatol*. 2022 Sep;40(8):1609. doi: 10.55563/clinexprheumatol/5geh4b. Epub 2022 Sep 15. PMID: 36106539.

Link: <https://doi.org/10.55563/clinexprheumatol/5geh4b>

[2022]

An Opportunity to Harmonise the Approach to Patients' Care Pathways for Rare and Complex Diseases: RarERN Path™

Talarico R, Marinello D, Cannizzo S, Palla I, Ticciati S, Gaglioti A, Rys A, Milli C, Taruscio D, Mosca M, Turchetti G. An Opportunity to Harmonise the Approach to Patients' Care Pathways for Rare and Complex Diseases: RarERN Path™. *Front Health Serv*. 2022 Jul 13;2:935014. doi: 10.3389/frhs.2022.935014. PMID: 36925875; PMCID: PMC10012666.

[2022]

The added value of a European Reference Network on rare and complex connective tissue and musculoskeletal diseases: insights after the first 5 years of the ERN ReCONNET

Talarico R, Aguilera S, Alexander T, Amoura Z, Andersen J, Arnaud L, Avcin T, Marsal Barril S, Beretta L, Bombardieri S, Bortoluzzi A, Bouillot C, Bulina I, Burmester GR, Cannizzo S, Cavagna L, Chaigne B, Cornet A, Corti P, Costedoat-Chalumeau N, Dāvidsone Z, Doria A, Fenech C, Ferraris A, Fischer-Betz R, Fonseca JE, Frank C, Gaglioti A, Galetti I, Guimarães V, Hachulla E, Holmner M, Houssiau F, Iaccarino L, Jacobsen S, Limper M, Malfait F, Mariette X, Marinello D, Martin T, Matthews L, Matucci-Cerinic M, Meyer A, Milas-Ahić J, Moinzadeh P, Montecucco C, Mouthon L, Müller-Ladner U, Nagy G, Patarata E, Pileckyte M, Pruunsild C, Rednic S, Romão VC, Schneider M, Scirè CA, Smith V, Sulli A, Tamirou F, Tani C, Taruscio D, Taulaigo AV, Tincani A, Ticciati S, Turchetti G, van Hagen PM, van Laar JM, Viera A, de Vries-Bouwstra JK, Zschocke J, Cutolo M, Mosca M. The added value of a European Reference Network on rare and complex connective tissue and musculoskeletal diseases: insights after the first 5 years of the ERN ReCONNET. *Clin Exp Rheumatol*. 2022 May;40 Suppl 134(5):3-11. doi: 10.55563/clinexprheumatol/d2qz38. Epub 2022 Mar 29. PMID: 35349419.

Link: [10.55563/clinexprheumatol/d2qz38](https://doi.org/10.55563/clinexprheumatol/d2qz38)

[2021]

A systematic literature review of existing tools used to assess medication adherence in connective tissue diseases: the state of the art for the future development of co-designed measurement tools

Pirri, S., Talarico, R., Marinello, D., Turchetti, G., & Mosca, M. (2021). A systematic literature review of existing tools used to assess medication adherence in connective tissue diseases: the state of the art for the future development of co-designed measurement tools. *Reumatismo*, 73(3). <https://doi.org/10.4081/reumatismo.2021.1418>.

Link: <https://doi.org/10.4081/reumatismo.2021.1418>

[2021]

Empowering Patients in the Therapeutic Decision-Making Process: A Glance Into Behçet's Syndrome

Marinello D, Di Cianni F, Del Bianco A, Mattioli I, Sota J, Cantarini L, Emmi G, Leccese P, Lopalco G, Mosca M, Padula A, Piga M, Salvarani C, Taruscio D and Talarico R (2021) Empowering Patients in the Therapeutic Decision-Making Process: A Glance Into Behçet's Syndrome. *Front. Med*. 8:769870. doi:10.3389/fmed.2021.769870.

Link: [10.3389/fmed.2021.769870](https://doi.org/10.3389/fmed.2021.769870)

[2021]

Being a caregiver of a Behçet's syndrome patient: challenges and perspectives during a complex journey

Talarico, R., Marinello, D., Manzo, A. et al. Being a caregiver of a Behçet's syndrome patient: challenges and perspectives during a complex journey. *Orphanet J Rare Dis* 16, 436 (2021). <https://doi.org/10.1186/s13023-021-02070-2>.

Link: <https://doi.org/10.1186/s13023-021-02070-2>

[2020]

Adherence to treatment in Behçet's syndrome: a multi-faceted issue

Pirri S, Marinello D, Lorenzoni V, Andreozi G, Bazzani A, Del Bianco A, Turchetti G, Mosca M, Talarico R. Adherence to treatment in Behçet's syndrome: a multi-faceted issue. *Clin Exp Rheumatol*. 2021 Sep-Oct;39 Suppl 132(5):88-93. Epub 2021 Sep 30. PMID: 34596034.

[2020]

The impact of COVID-19 on rare and complex connective tissue diseases: the experience of ERN ReCONNET

Talarico R, Aguilera S, Alexander T, Amoura Z, Antunes AM, Arnaud L, Avcin T, Beretta L, Bombardieri S, Burmester GR, Cannizzo S, Cavagna L, Chaigne B, Cornet A, Costedoat-Chalumeau N, Doria A, Ferraris A, Fischer-Betz R, Fonseca JE, Frank C, Gaglioti A, Galetti I, Grunert J, Guimarães V, Hachulla E, Houssiau F, Iaccarino L, Krieg T, Limper M, Malfait F, Mariette X, Marinello D, Martin T, Matthews L, Matucci-Cerinic M, Meyer A, Montecucco C, Mouthon L, Müller-Ladner U, Rednic S, Romão VC, Schneider M, Smith V, Sulli A, Tamirou F, Taruscio D, Taulaigo AV, Terol E, Tincani A, Ticciati S, Turchetti G, van Hagen PM, van Laar JM, Vieira A, de Vries-Bouwstra JK, Cutolo M, Mosca M. The impact of COVID-19 on rare and complex connective tissue diseases: the experience of ERN ReCONNET. *Nat Rev Rheumatol*. 2021 Mar;17(3):177-184. doi: 10.1038/s41584-020-00565-z. Epub 2021 Jan 6. PMID: 33408338; PMCID: PMC7786339.

[2020]

Patient engagement in healthcare: a preliminary set of measures to evaluate patient engagement in the European Reference Networks

Marinello D, Galetti I, Dan D, Andersson AS, Aguilera S, Lousse S, Wiehe L, Aslanian AL, Martin IH. Patient engagement in healthcare: a preliminary set of measures to evaluate patient engagement in the European Reference Networks. *Rare Dis Orphan Drugs J* 2021;1:2. <http://dx.doi.org/10.20517/rdodj.2021.001>

[2019]

RarERN Path: a methodology towards the optimisation of patients' care pathways in rare and complex diseases developed within the European Reference Networks

Talarico, R., Cannizzo, S., Lorenzoni, V. et al. Correction to: RarERN Path: a methodology towards the optimisation of patients' care pathways in rare and complex diseases developed within the European Reference Networks. *Orphanet J Rare Dis* **16**, 146 (2021). <https://doi.org/10.1186/s13023-021-01778-5>

[2019]

Shaping the Future of Rare Diseases after a Global Health Emergency: Organisational Points to Consider

Talarico R, Marinello D, Cannizzo S, Gaglioti A, Ticciati S, Carta C, Kodra Y, Azadegan M, Taruscio D, Mosca M, Turchetti G. Shaping the Future of Rare Diseases after a Global Health Emergency: Organisational Points to Consider. *Int J Environ Res Public Health*. 2020 Nov 23;17(22):8694. doi: 10.3390/ijerph17228694. PMID: 33238523; PMCID: PMC7700629.

[2019]

Clinical practice guidelines adherence, knowledge and awareness in rare and complex connective tissue diseases across Europe: results from the first ERN ReCONNET survey

Talarico R, Marinello D, Bombardieri S, Burmester G, Fonseca J, Frank C, Galetti I, Hachulla E, Houssiau F, Mueller-Ladner U, Schneider M, Smith V, Turchetti G, van Laar JM, Vieira A, Cutolo M, Mosca M. Clinical practice guidelines adherence, knowledge and awareness in rare and complex connective tissue diseases across Europe: results from the first ERN ReCONNET survey. *RMD Open*. 2020 Aug;6(2):0. doi: 10.1136/rmdopen-2020-001344. PMID: 32868449; PMCID: PMC7507993.

DIGITAL SKILLS

Microsoft Word / Microsoft Excel / Microsoft Powerpoint / Microsoft Office / Outlook / Zoom / Skype / Facebook / Social Media / Power Point / Organizational and planning skills / Decision-making / EU Survey