# Diana Marinello

📍 Home :

✉ Email:  📞 Phone:

Date of birth:  Nationality:

## WORK EXPERIENCE

[ 05/2017 – Current ]

### Network and Project Manager ERN ReCONNET

*Azienda Ospedaliero Universitaria Pisana*

**City:** Pisa

**Country:** Italy

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

Main tasks: assist the Network Coordinator in the strategic and operational management of ERN ReCONNET, ensuring the implementation of the ERN objectives, promote an appropriate engagement and effective collaboration among all the members, affiliated partners, ePAG Advocates and stakeholders of ERN ReCONNET, being a contact reference point for the Network; lead the ERN ReCONNET Policies and Procedures development, management and implementation, lead the monitoring of the HCPs Performance, Loss of Membership Policy and the Assessment and Evaluation processes of the ERN ReCONNET, together with the other members of the Coordination Team, support to the scientific coordinator in the activities of the Network related to Clinical Practice Guidelines and research, including the preparation of protocols, abstracts and scientific publications, coordinate the patients' partnership and involvement in ERN ReCONNET, promoting an active involvement of the ePAGs in the activities of the Network, manage, together with the Network Coordinator and the Scientific Coordinator, the strategic collaboration with other ERNs and other initiatives, supervise the ERN Continuous Monitoring and ERN ReCONNET Quality Improvement System and the ERN Evaluation, lead the ERN Grant Proposals preparation, submission, implementation and technical reporting, together with the other members of the Coordination Team; advise ERN Members in following the ERN policies and procedures and provide guidance to the ERN ReCONNET Working Groups and Disease Groups; to supervise the development of the educational and training activities of the ERN to ensure compliance with EC's and Network's requirements, oversee with the Network Coordinator and the Financial Administrative Manager, the recruiting of the ERN Coordination Team staff members, lead the development of Surveys, questionnaires and online forms developed in ERN ReCONNET, perform the required Programme and Project Management activities, including keeping track of the status of the activities of the Network.

Grants related to this position:

"European Reference Network on Rare Connective Tissue and Muskuloskeletal Diseases - ERN ReCONNET", Call: EU4H-2022-ERN-IBA-01, GA n° 101085769 01/03/2022-31/08/2023;

"European Reference Network on Rare Connective Tissue and Muskuloskeletal Diseases - ERN ReCONNET", Call: HP-ERN-SGA-2018, GA n° 847115 01/03/2019-28/02/2022;

"European Reference Network on Rare Connective Tissue and Muskuloskeletal Diseases - ERN ReCONNET", Call: HP-ERN-SGA-2017, GA n° 811633 01/03/2018-28/02/2019;

"European Reference Network on Rare Connective Tissue and Muskuloskeletal Diseases - ERN ReCONNET", Call: HP-ERN-SGA-2016, GA n° 769019 06/05/2017 al 28/02/2018.

[ 03/2020 – Current ]

### Project Manager

*Azienda Ospedaliero Universitaria Pisana*

**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), coordination of the patients' involvement, coordination of the Working Group and of the activities related to the Mapping of existing rCTDs registries, preparation of scientific manuscripts, in charge of the preparation of grant proposals and support in grant management, preparation of deliverables.
Grant related to this position:
"TogethERN ReCONNET", Call HP-PJ-2019, GA N° 947700, 01/03/2020-ongoing.

**[ 05/2018 – Current ]**

## Project Manager

### *Azienda Ospedaliero Universitaria Pisana*

**City:** Pisa

**Country:** Italy

Coordination of the ERN ReCONNET National Hubs, Member of the ERN ReCONNET Operational Helpdesk, Support in the management of the virtual clinical panels, Project Management, in charge of the preparation of the proposals and support in grant management, preparation of deliverables.
Grants related to this position:
"ERN ReCONNET Operational Helpdesk", CEF TELECOM CALL FOR PROPOSALS 2018 CEF-TC-2018-4, GA N° INEA/CEF/ICT/A2017/1529301, 01/05/2018 al 30/11/2019;
"ERN ReCONNET IT Services", CEF TELECOM CALL FOR PROPOSALS 2018 CEF-TC-2018-4, GA N° INEA/CEF/ICT/A2018/1817686, 01/12/2019 al 30/11/2021.
"ENROLLMENT, ErN RecOnnet cLinicaL patient ManagemENT", European Health and Digital Executive Agency (HaDEA) action number 2020-IT-IA-0259, Agreement number: INEA/CEF/ICT/A2020/2397627, 01/12/202-ongoing.

**[ 10/2015 – 05/2017 ]**

## International and European Project Manager

### *SIMBA OdV*

**Country:** Italy

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

**[ 08/2013 – 07/2015 ]**

## Language school teacher

### *vhs Kaufbeuren*

**City:** Kaufbeuren
**Country:** Germany
Italian language teacher for German speakers

## EDUCATION AND TRAINING

**[ 05/2023 ]**

## Narrative Medicine Facilitator

### *SIMeN | Società Italiana di Medicina Narrativa*

**[ 09/2022 ]**

## Master in Applied Narrative Medicine

### *ISTUD*

**[ 03/2022 ]**

## Master in Methodologies supporting patient engagement and communication

**[ 11/2021 ]**

## Cura alle stelle - Narrative Medicine and health narratives

### *SIMeN | Società Italiana di Medicina Narrativa*

**[ 08/2021 ]** **Orphanet nomenclature and Orphanet Rare Disease Ontology**

*Orphanet*

**[ 03/2021 ]** **Traning on ICH Good Clinical Pratice Guidelines**

*AVANTYO Institute of Clinical Research*

**[ 11/2020 ]** **EURORDIS Leadership School on Healthcare & Research**

**[ 08/2020 ]** **International Summer School on Rare Disease Registries and FAIRification of Data**

**[ 07/2020 ]** **Project Management advanced course**

*Stargate Consulting*

**[ 05/2019 ]** **Licence for the Morisky Widget MMAS-8 medication adherence and medication reconciliation**

**[ 05/2018 ]** **Eurordis Summer School on medicines research and development**

**[ 02/2018 ]** **Project Management Certificate**

*Italian Project Management Institute*

**[ 03/2008 ]** **Degree in Foreign languages**

*Roma Tre University*

## LANGUAGE SKILLS

**Mother tongue(s):** Italian

**Other language(s):** English , German , French

## 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

## PUBLICATIONS

**[ 05/2023 ]** **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. 2023 May 22. doi: 10.1007/s10198-023-01593-8. Epub ahead of print. PMID: 37212892.

**[ 03/2023 ]**

**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, Andreozzi 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.

**[ 03/2023 ]**

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

Talarico R, Ramirez GA, Barreira SC, Cardamone C, Triggianese P, Aguilera S, Andersen J, Avcin T, Benistan K, Bertsias 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.

**[ 01/2023 ]**

**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, Sáez Comet L, 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 Jan 15:jrheum.220773. doi: 10.3899/jrheum.220773. Epub ahead of print. PMID: 36642433.

**[ 01/2023 ]** **Sleep quality in Behçet's disease: a systematic literature review**

Italiano N, Di Cianni F, Marinello D, Elefante E, Mosca M, Talarico R. Sleep quality in Behçet's disease: a systematic literature review. Rheumatol Int. 2023 Jan;43(1):1-19. doi: 10.1007/s00296-022-05218-w. Epub 2022 Oct 4. PMID: 36194239; PMCID: PMC9839818.

**[ 12/2022 ]**

**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

[ 07/2022 ]

**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

[ 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

[ 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, Andreozzi 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.

[ 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

[ 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, Louisse 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.

**ADDITIONAL INFORMATION**

**Member of the Italian Society for Narrative Medicine**

**Member of the ERN Monitoring and Quality Improvement System Working Group**

[ 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, Ticclati 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 ]

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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.

## ADDITIONAL INFORMATION

Member of the Italian Society for Narrative Medicine


Member of the ERN Monitoring and Quality Improvement System Working Group


Autorizzo il trattamento dei dati personali ai sensi del Regolamento UE n 679/2016 e del Dlgs n.196 e successive modificazioni