European League Against Rheumatism

RCN and BSR Joint Rheumatology Conference Feb 2015

Professor Anthony Redmond, Chair-elect, EULAR HP Standing Committee

email: a.redmond@leeds.ac.uk
Why is Europe/EULAR relevant?

• UK nursing already leads the way in rheumatology care in Europe!
• Still opportunities to learn from others
• De-medicalization of long-term conditions presents opportunities
• Multidisciplinary care increasingly important
  • Nursing (and EULAR) are active and powerful advocates
• A rising tide floats all the boats
An umbrella organisation encompassing 45 nations

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eular
EULAR institutional members

representing 120 million people with rheumatic and musculoskeletal diseases (RMD) in Europe
The 2014 Member directory

Contact details and membership for all HP member countries

www.eular.org
Österreichische Gesellschaft für rheumatologische Gesundheitsberufe (ÖGRG)

Secretariat Office
Boehrenwegasse 3/12, 1030 Wien, Austria

President
Ms. Margit Bruckner
margbruckner@gmail.com

Treasurer
Ms. Iris Lug

General Secretary
Ms. Martina Sadonova

Liaison Officer with EULAR
Ms. Michaela Stoffer
michaela.stoffer@eula.org

HP member structure
Number of members: 80
Health professional disciplines presented
Nurses 68 %
Occupational therapists 16 %
Physiotherapists 6 %
Psychologists 0 %
Social workers 0 %
Podiatrists 0 %
Nutritionists 6 %
Rheumatologist representatives 0 %
Patient representatives 0 %
Other professionals/representatives
Medical technical assistants 3 %
Others 1 %

About the organisation
The association was founded in 2012 and became a member of EULAR in 2013.

Website
Under construction.

Aims of the organisation
The association aims to empower health professionals specialized in rheumatic and musculoskeletal diseases to co-operate, benefit from interdisciplinary know-how and make use of the latest European recommendations for good care.

Main activities
The association has an annual assembly meeting, attends EULAR congresses and is organizing a specialization course for health professionals in rheumatology.
Overall EULAR mission

• reduce the burden of rheumatic diseases on the individual and society

• improve the treatment, prevention and rehabilitation of musculoskeletal diseases

• foster excellence in education and research in the field of rheumatology

• Promote translation of research advances into daily care

• Fight for the recognition of the needs of people with rheumatic diseases

• Represent the interests of the entire rheumatic disease community on the EU level
EULAR standing committees

- Investigative rheumatology
- Clinical affairs
- Education and training
- Epidemiology and health services research
- Musculoskeletal imaging
- Paediatric rheumatology
- Patients (PARE)
- Health professionals
The EULAR journals –
Annals of Rheumatic Diseases and RMD Open

ARD
• Frequency: monthly
• Impact factor: 9.27
• First publication: 1939

RMD Open
• Frequency: continuous
• Impact factor: Not yet
• First publication: 2015 vol1
The EULAR Annual Congress of Rheumatology

- 12,000 to 16,000 delegates
- Major lecture programme
- Extensive scientific/clinical research programme
- Networking opportunities
- Formal groups and business meetings
Country Membership of EULAR

- Voting at Annual General Meeting
- Representation on HP Standing Committee
- Networking & collaboration with others
Study Groups

- Currently six active study groups
- Two for nursing

**EULAR nurses study group Research and Strategy (REST)** research agenda and an educational agenda that increasingly leads to European and global initiatives from rheumatology nurses.  
*Yvonne van Eijk-Hustings, lead (Netherlands)*

**EULAR Clinical Nurse Study Group** promotes nursing collaboration on key clinical and developmental issues in nursing.  
*Jenny de La Torre, lead (Spain)*
UK nursing well represented

EXTENDED REPORT

The outcome and cost-effectiveness of nurse-led care in people with rheumatoid arthritis: a multicentre randomised controlled trial

Mwidimi Ndosi,1 Martyn Lewis,2 Claire Hale,1,3 Helen Quinn,3 Sarah Ryan,4 Paul Emery,5,6 Howard Bird,5 Jackie Hill1

EXTENDED REPORT

Validation of the educational needs assessment tool as a generic instrument for rheumatic diseases in seven European countries

Mwidimi Ndosi,1 Ann Bremander,2 Bente Hamnes,3 Mike Horton,4 Marja Leena Kukkurainen,5 Pedro Machado,6 Andrea Marques,6 Jorit Meesters,7 Tanja A Stamm,8 Alan Tennant,4 Jenny de la Torre-Abo,9 Theodora P M Vliet Vlieland,7 Heidi A Zangi,10 Jackie Hill1
EXTENDED REPORT

Shared care or nursing consultations as an alternative to rheumatologist follow-up for rheumatoid arthritis outpatients with low disease activity—patient outcomes from a 2-year, randomised controlled trial

Jette Primdahl,1,2 Jan Sørensen,3 Hans Christian Horn,4 Randi Petersen,2 Kim Hørslev-Petersen1,2

EXTENDED REPORT

Patients’ needs and expectations with regard to rheumatology nursing care: results of multicentre focus group interviews

Yvonne van Eijk-Hustings,1 Judy Ammerlaan,2 Hanneke Voorneveld-Nieuwenhuis,3 Bertha Maat,4 Conny Veldhuizen,5 Han Repping-Wuts6

EXTENDED REPORT

Impact of a nurse-led programme on comorbidity management and impact of a patient self-assessment of disease activity on the management of rheumatoid arthritis: results of a prospective, multicentre, randomised, controlled trial (COMEDRA)

Maxime Dougdos,1 Martin Soubrier,2 Elodie Perrodeau,3 Laure Gossec,4 Françoise Fayet,2 Mélanie Gilson,5 Marie-Hélène Cerato,6 Sophie Pouplin,7 René-Marc Filpo,8 Laurent Chabrely,9 Gael Mouterde,10 Liana Euler-Ziegler,11 Thierry Schaeverbeke,12 Bruno Fautrel,13 Alain Saraux,14 Isabelle Chary-Valckenaere,15 Gérard Chales,16 Emmanuelle Dernis,17 Pascal Richette,18 Xavier Mariette,19 Francis Berenbaum,20 Jean Sibilia,21 Philippe Ravau22
EULAR Recommendations for management

EULAR recommendations for management

George K Bertias, Maria Tektonidou, Zahir Amoura, Martin Aringer, Ingeborg Bajema, Jo H M Berden, John Boletis, Ricard Cervera, Thomas Dörner, Andrea Doria, Franco Ferrario, Jürgen Floege, Frederic A Houssiau, John P A Ioannidis, David A Isenberg, Cees G M Kallenberg, Liz Lightstone, Stephen D Marks, Alberto Martini, Gabriela Moroni, Irmgard Neumann, Manuel Praga, Matthias Schneider, Argyre Starra, Vladimir Tesar, Carlos Vasconcelos, Ronald F van Vollenhoven, Helena Zakharova, Marion Haubitz, Caroline Gordon, David Jayne, Dimitrios T Boumpas

Joint European League Against Rheumatism and European Renal Association-European Dialysis and Transplant Association (EULAR/ERA-EDTA) recommendations for the management of adult and paediatric lupus nephritis

Ann Rheum Dis doi:10.1136/annrheumdis-2012-201940 Published Online First 31 July 2012
Read this recommendation >>

Source: www.eular.org
EULAR Recommendations for conducting/reporting clinical trials

EULAR recommendations for conducting/reporting clinical trials

Christian Beyer, Jörg H W Distler, Yannick Allanore, Martin Aringer, Jérôme Avouac, László Czirjak, Maurizio Cutolo, Nemanja Damjanov, Francesco Del Galdo, Kim Fligelstone, Serena Guiducci, Otylia Kowal-Bielecka, Jacob M van Laar, Marco Matucci-Cerinic, Ulf Müller-Ladner, Gabriela Riemekasten, Ingo H Tarner, Alan Tyndall, Ann Tyrrell Kennedy, Gabriele Valentini, Serena Vettori, Ulrich A Walker, Christopher Denton, Oliver Distler, the EUSTAR Biobanking Group

EUSTAR biobanking: recommendations for the collection, storage and distribution of biospecimens in scleroderma research

Ann Rheum Dis 2011;70:1178-1182 doi:10.1136/ard.2010.142489 Published Online First 1 February 2011

Read this recommendation >>


European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects

Ann Rheum Dis 2011;70:722-726 Published Online First: 20 January 2011

Read this recommendation >>
EULAR classification and diagnosis criteria/response criteria

EULAR Classification and diagnosis criteria / response criteria


EULAR recommendations for terminology and research in individuals at risk of rheumatoid arthritis: report from the Study Group for Risk Factors for Rheumatoid Arthritis

Read this recommendation >>

Source: www.eular.org
EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis

Yvonne van Eijk-Hustings,1 Astrid van Tubergen,2 Carina Boström,3 Elena Braychenko,4 Beate Buss,5 José Felix,6 Jill Firth,7 Alison Hammond,8 Benny Harston,9 Cristina Hernandez,10 Masa Huzjak,11 Jana Korandová,12 Marja Leena Kukkurainen,13 Robert Landewé,14 Maryse Mezieres,4 Marijana Milincovic,15 Antonella Moretti,15 Susan Oliver,16 Jette Primdahl,17,18 Marieke Scholte-Voshaar,19 Jenny de la Torre-Aboki,20 Jennifer Waite-Jones,7 Rene Westhovens,21 Heidi Andersen Zangi,22 Turid Heiberg,23,24 Jackie Hill25

ABSTRACT

Objectives The authors aim to develop European League Against Rheumatism recommendations for the role of the nurse in the management of patients with chronic inflammatory arthritis, to identify a research agenda and to determine an educational agenda.

Methods A task force made up of a multidisciplinary expert panel including nurses, rheumatologists, occupational therapist, physiotherapist, psychologist, epidemiologist and patient representatives, representing 14 European countries, carried out the development of the recommendations, following the European League. However, there are large differences across countries and regions. In several European countries, rheumatology as a nursing specialty does not exist, whereas in other countries, it has developed into a recognised specialty with nurses undertaking advanced and extended roles. These include self-management support, patient education and counselling, intra-articular injections, recommendation for and the prescription of drug treatments, referral to other health professionals, hospital admission of patients, manning telephone advice lines and monitoring disease-modifying and biological
EULAR general educational activities

**EULAR Textbook on Rheumatic Diseases**

**EULAR on-line courses:**
- EULAR On-line Course on Rheumatic Diseases
- EULAR On-line Course on CTD
- EULAR On-line Course on SSc
- EULAR On-line Introductory Ultrasound Course

**EULAR live courses:**
- EULAR Ultrasound Course
- EULAR Ultrasound Trainer Course
- EULAR SLE Course
- EULAR Capillaroscopy Course
- EULAR Epidemiology Course
- EULAR Health professional teachers Course
- EULAR Postgraduate Course/Fellow Days

**EULAR video production:**
the GALS examination
EULAR On-line Course for Health Professionals

This EULAR On-line Course for Health Professionals focusses on two major musculoskeletal and rheumatic conditions: rheumatoid arthritis (RA) and osteoarthritis (OA) and is aimed at health professionals (HPs) who play an important role in the management of these conditions: nurses, physical therapists, occupational therapists and psychologists.

It consists of a total of 8 modules: 4 disease-specific modules (one on RA, one on OA, one on Fibromyalgia and one on regional musculoskeletal pain syndromes) and 4 generic modules (assessment and evaluation; interventions; psychosocial approaches and evidence-based practice). Care is given to integrate the multi-disciplinary perspective of the treatment of rheumatic diseases.

The duration of the course is 9 months with an automatic free of charge extension of a second year if the modules are not completed or the exam not passed. A final examination is offered once a year and a EULAR certificate is issued upon passing the exam.

The on-line course was developed with a substantial grant from EULAR and is continuously highly subsidised by EULAR, so that the entire course can be offered at EUR 100 per participant.

More information on http://www.eular.org/edu_online_course_hpr.cfm
Course start: September 2015 – registration now open
First draft working plan for the development of a core curriculum for HPs (2015)

The working plan:
• Based on the results of telephone interviews and survey among HPs
• Includes a Delphi process on proposed elements of the core educational curriculum with relevant stakeholders
• Takes into account parallel HP projects on educational activities (HP US course, Definition of general core competencies for HPs working in rheumatology)
Mentoring for HPs

- Led by Jo Adams (Southampton)
- Loosely based on NIHR model
- Currently scoping /recruiting

1. What tasks/skill development would you think may be relevant and feasible to include as part of a European wide mentorship programme?

2. Would you be willing to act as an academic mentor to a European health professional and if so what skills could you bring to this role?

ja@soton.ac.uk

March 6, 2015
EULAR bursaries and grants

Congress bursaries:
350 EUR cash, 3 nights accommodation, 1 year free subscription to the ARD
• 155 bursaries for rheumatologists
• 30 bursaries for health professionals
• 15 bursaries for patients

Educational grants:
• 10 scientific training grants for rheumatologists
  (3-6 months training in another European clinic)
• 10 educational visit grants for health professionals
  between 750 € and 1500€
• a predefined educational visit grant for patient organisations
Newsletter – Winter 2014

Edited by Kate Betteridge

Direct download at:

Visit www.eular.org
Strategic objective 1 - Research
By 2017, EULAR will be a central platform to facilitate and stimulate innovative basic and clinical research projects in rheumatic and musculoskeletal diseases.

By 2017, EULAR will have facilitated funding/sponsoring of major basic/clinical (including trials) science projects through the European Rheumatology Research Foundation (ERRF).

By 2017, EULAR will have increased the quantity and quality of HP-led research projects and strengthened patient participation.

By 2017, EULAR will have established a structure to coordinate standardisation and collaboration of national datasets including observational studies, registries and cohorts.
Research objectives 2015-2017

• Quantify HP research activity
• Assess quality
• Promote patient involvement
• Facilitate clinician involvement in research
• Facilitate uptake dissemination and implementation

• HP-led FOREUM application
EULAR and the European Union

EULAR is actively advocating for the interests and needs of the RMD community to be adequately represented in both Horizon 2020 and EY2012.

Chair HPSC a member of EU Affairs Group.
EU Affairs

Activities within EU parliament and European Commission

Raise profile of RMDs – as a chronic condition

Encourage European Commission to invest RMD healthcare and research

Led by Neil Betteridge (PARE)
ESCHPR representative Anthony Redmond
EU Policy & Political issues and priorities

- Access to health care
- Chronic Diseases
- Cross-border health care
- Standards of care

- Horizon 2020
- Roadmap
- Data Protection

- EU Disability legislation
- Health & Safety at work

Strengthening relations with new Commission, Parliament and next EU Presidencies
Summary

1. UK nursing already leads the way in rheumatology care in Europe
2. Still opportunities to learn from others
3. Move away from medicalization of LTCs presents significant opportunities
4. Multidisciplinary care increasingly important and nursing (and EULAR) are active and powerful advocates
5. A rising tide floats all the boats

www.eular.org /a.redmond@leeds.ac.uk
For more information visit the EULAR website: www.eular.org