

## European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases, 2009-2014

### Report

#### Introduction

The **European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases** (RMDs) was created in 2009 on the occasion of the World Arthritis Day (12 October) and was active during the full Parliamentary term 2009-2014.

The goal of the Interest Group (IG) was to raise awareness of the enormous social and economic burden of RMDs on European societies. More importantly, it aimed at shaping the political input of the European Parliament for future EU legislation and programmes, ensuring that these diseases were made an integral part of EU programmes in health, research, social affairs, employment and other relevant policies. The IG 2009-2014 was comprised of 25 MEPs from different political groups, nationalities and committees (see Appendix 1). In average, the IG met three times per year, each time focusing on a different topic.

EULAR has run the Secretariat of the IG since its creation in 2009. Among other activities, the Secretariat has:

- Coordinated the overall activities of the group
- Proposed the topic and the agenda for meetings
- Organised the IG meetings
- Briefed MEPs and provided support to MEPs interventions
- Liaise with stakeholders and other institutions on behalf of the IG

This paper provides a summary of the IG activities and results.

#### Topics

Each IG meeting focused on a specific policy-related aspect of RMDs, covering the main EU policy areas having an impact on these diseases: research, public health and employment & social affairs.

Topics were selected according to their potential contribution to policy developments at the time of each meeting.

Themes covered by the IG are listed below in a sequential order<sup>1</sup>:

- Research and Innovation: Contributions to the next EU Research Framework Programme
- Rheumatic and Musculoskeletal Diseases at Work
- European Parliament Input to the Belgian Presidency Focus on Rheumatic and Musculoskeletal Diseases

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<sup>1</sup> For a brief description of the discussion of each meeting, please see Appendix 2. Minutes of all meetings can be downloaded from the EULAR website.

- Health Inequalities in the Development, Prevention and Treatment of Rheumatic and Musculoskeletal Diseases across Europe
- Research trends in health – The role of RMDs in current and future Research Framework Programmes
- RMDs and Active and Healthy Ageing
- Social and economic costs of RMDs
- Towards an EU strategy on chronic diseases: A follow-up of the Council Conclusions on chronic diseases
- RMDs and Pain: Facts and Finding
- The EU post-2014 budget and the future of health research: Redefining priorities, improving effectiveness
- New Disability Law: Does it help people with chronic diseases?
- New Data Protection Legislation: Consequences for Health Research
- What EU Public Health Policies for 2014-2019?

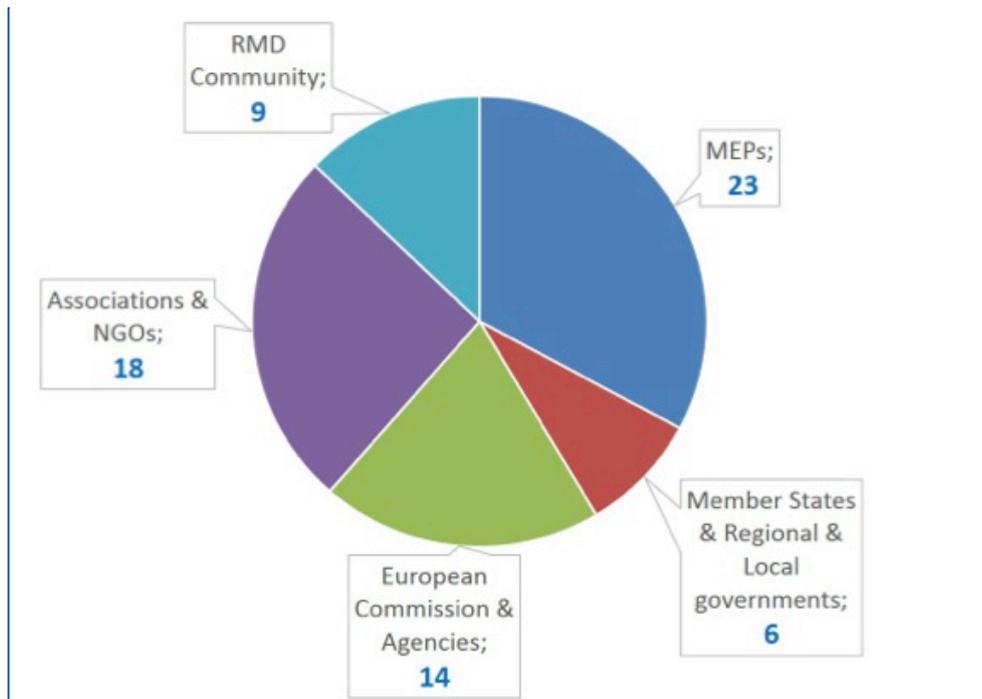
## **Speakers and participants**

The discussions of the Interest Group have sought to reflect the multi-faceted nature of the issue, highlighting musculoskeletal diseases from the perspectives of different EU institutions and stakeholders.

On each topic, the meetings typically included a presentation by the European Commission on existing or planned policy initiatives or legislation, and the corresponding opinion of the Member States (including three Council Presidencies) and the European Parliament. In addition, a representative of the RMD community as well as key stakeholders were invited to present their views.

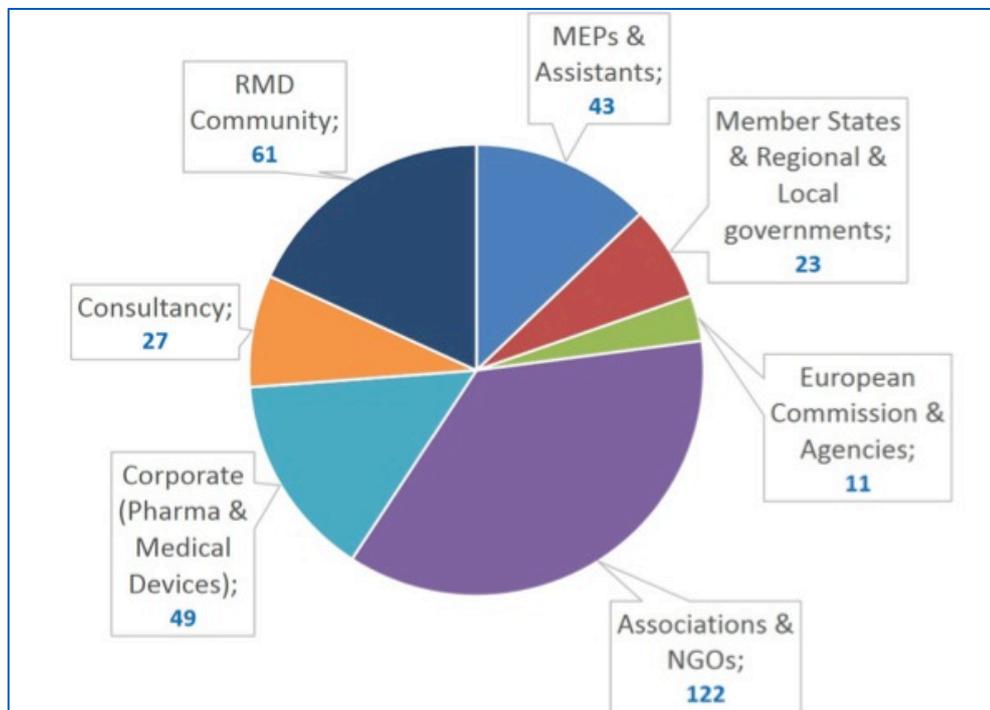
For each IG meeting, a number of participants were invited to attend and contribute to the discussion. In total, 244 ordinary participants representing 96 different organisations participated in the 13 meetings of the Interest Group (see Figure 2). The average number of participants per meeting has been 31,5. In comparison with similar European Parliament Interest Groups, the IG on RMDs is therefore considered a very well attended event.

**Figure 1: Speakers**



**Figure 2: Ordinary participants**

Note: The chart represents the number of participants that attended at least



one of the IG meetings.

## Evaluation & Preliminary appraisal

EULAR is currently undertaking an evaluation of the IG. For this, it has invited participants to answer a questionnaire. The results are expected to be ready before the summer break.

According to the preliminary feedback got from a number of MEPs, representatives of other EU institutions and participants, the IG on RMDs has a high reputation. Among others, it has been mentioned the following positive aspects:

- **High quality speakers and participants.** Members of Commissioners' cabinets, Head of Units, and Commission's experts on different themes have presented at the meeting. In addition, high level representatives of relevant stakeholders have participated in the meetings.
- **Well-attended meetings.** As mentioned above, 31,5 persons in average have attended each of the meetings. This has allowed for rich discussions around different topics.
- **High interest in IG outputs.** Each meeting has focused on a relevant, timely topic. They were usually linked to the development of policy initiatives taking place by the time of the meeting (or soon after). In this sense, the IG has contributed to the debate around those initiatives, by inviting key policy makers to present their opinions. MEPs, representatives of the European Commission, the EU Council and other EU institutions have found these meetings useful. The RMD community could also use this exchange of ideas with policy makers to express their thoughts and perspectives on different policy issues.

## Next steps

One of the main goals of EULAR EU Affairs for the coming months is to establish a new Interest Group on RMDs during the next Parliamentary term (2014-2019). To this end, it has contacted all MEP candidates in all Member States during the last months. The aim of this campaign was to raise awareness on the burden of RMD among candidates, as well as to identify potential champions and supporters in the new Parliament.

In the coming weeks, EULAR will be contacting elected MEPs, with the aim of establishing a new IG and engage MEPs in EULAR activities.

**Appendix 1:**  
**Members of the European Parliament Interest Group on**  
**Rheumatic and Musculoskeletal Diseases**

<b>Chair</b>	
Edite Estrela	Portugal
<b>Vide-Chair</b>	
Jim Higgins	Ireland
Antonyia Parvanova	Bulgaria
Marije Cornelissen	Netherlands
Sir Robert Atkins	UK
Takis Hadjigeorgiou	Cyprus
<b>Members</b>	
Jan Philipp Albrecht	Germany
Nessa Childers	Ireland
Pat the Cope Gallagher	Ireland
Sean Kelly	Ireland
Roger Helmer	UK
Gay Mitchell	Ireland
Claude Moraes	UK
Siiri Oviir	Estonia
Justas Vincas Paleckis	Lithuania
Antigoni Papadopoulou	Cyprus
Ioan Mircea Paşcu	Romania
Alojz Peterle	Slovenia
Anna Rosbach	Denmark
Paul Rübig	Austria
Theodoros Skylakakis	Greece
Kyriacos Triantaphyllides	Cyprus
Eleni Theocharous	Cyprus
Patrizia Toia	Italy
Rodi Kratsa-Tsagaropoulou	Greece

## Appendix 2: Summary of IG meetings

### 1st Meeting (03 December 2009)

*“Research and Innovation: Contributions to the next EU Research Framework Programme”*

The first meeting officially constituted the Interest Group, setting up the working programme, dates and topics to be covered in subsequent meetings. **Dr Grigorij Kogan** (Scientific Officer for Chronic Diseases, DG Research, European Commission) presented the place that RMDs occupy in the FP7 programme. He gave an overview of the numerous initiatives under the umbrella of FP7 that aim at researching the causes of muscular disorders and improving clinical care for those affected. The projects deal with arthritis/osteoarthritis, osteoporosis and muscular degeneration in old age. A total of 16 projects were identified that include research into RMDs, to which the EU contributes roughly 90 million euros.

### 2nd Meeting (02 March 2010)

*“Rheumatic and Musculoskeletal Diseases at Work”*

This event discussed the barriers that people with RMD face in participating in the labour market due to inadequate working conditions. **Armando Silva** (Acting Director for Social Dialogue, Social Rights, Working Conditions and Adaptation to Change, Commission DG Employment, Social Affairs and Equal Opportunities) presented the European Commission’s initiatives to strengthen the implementation of existing Directives by Member States. However, a legislative framework alone is not sufficient – it must be completed by concrete guidelines for SMEs to create a more inclusive work environment. **Stephen Bevan** (Managing Director, The Work Foundation) presented that workplace inclusion of RMD patients is in severe stagnation. Employers have a low awareness of MSDs, many workers are not properly supported and medicines tend to sign people away from work. Hence, the Work Foundation wants the Commission to encourage national governments to introduce a framework on MSDs and to recognize them as political issues. **Marios Kouloumas** (Chairperson for People with Arthritis/Rheumatism in Europe, EULAR/PARE) presented the EULAR Work Charter, calling on the European Commission and Council as well as the European governments to recognise and enforce the employment rights of people with RMDs. Stakeholders expressed high expectations towards the Commission to take more assertive action and launch a Directive on enhanced inclusion in the workplace, which will oblige employers and governments alike.

### 3rd Meeting (06 July 2010)

*“European Parliament Input to the Belgian Presidency Focus on Rheumatic and Musculoskeletal Diseases”*

The meeting discussed the agenda of the Belgian Presidency regarding RMDs and other chronic diseases. **Pol Gerits** (Federal Public Service Health, Presidency Coordinator of the Belgian Health Ministry) presented the Presidency’s public health agenda. **Prof Anthony Woolf** (EULAR co-opted member of the Standing Committee on Education and Training) introduced the EU-MUSC.NET project, an EU- and EULAR-sponsored initiative aiming to develop an information surveillance system on RMDs. EU-MUSC.net sets and monitors standards of care of rheumatoid arthritis and osteoarthritis; identifies barriers that may prevent the effectiveness of treatments; and provides information on the impact of musculoskeletal conditions.

The discussion voiced clear dissatisfaction with the Commission’s weak stance on tackling RMDs and not making full use of EU-MUSC.NET. They demanded that the Commission shows stronger commitment to promoting RMD strategies and taking regulatory action, especially regarding health in the workplace. A joint hearing of the ENVI and EMPL committees was proposed to discuss more effective workplace regulations, and a written question to the Commission was suggested.

### 4th Meeting (30 November 2010)

*“Health Inequalities in the Development, Prevention and Treatment of Rheumatic and Musculoskeletal Diseases across Europe”*

**Ms Paula Duarte Gaspar** (European Commission, Member of Cabinet of Commissioner for Health, John Dalli) underlined the Commission’s commitment to addressing health inequalities. A speech by **Prof Ingemar Petersson** (Research Director MORSE, Musculoskeletal Research Centre in Southern Sweden) presented data on the socio-economic determinants at the heart of RMD health inequalities, stressing especially macroeconomic factors such as national wealth and education levels. **Kaisa Immonen-Charalambous** (Policy Officer, European Patients’ Forum) stressed that health inequalities could be partially alleviated if patients were given greater empowerment and ownership of the issue by including them more fully in policy-making processes.

### 5th Meeting (22 March 2011)

*“Research trends in health – The role of RMDs in current and future Research Framework Programmes”*

The aim of the 5<sup>th</sup> IG meeting was to discuss current and future developments in research and innovation in RMDs, as well as on the contribution of the EU and Member States in this field. **Ruxandra Draghia-Akli** (Director for Health, DG for Research and Innovation, European Commission) and **David Harmon** (Member of Cabinet, Commissioner for Research and Innovation, Máire Geoghegan-Quinn) presented a mid-term analysis of health policy in FP7. They highlighted the increased attention given to RMD research by the Commission. **Eric-Olivier Pallu** (Science and

Technology Counsellor, Permanent Representation of France to the EU) presented on research in health from a Member States' perspective, emphasising the need for greater interaction of different stakeholders between national and European levels.

**Prof Paul Emery** (EULAR President) stressed again the prevalence of these diseases (about 25% of European citizens suffer from RMDs), which constitute an enormous strain on European health and social care systems. Prof Emery also presented on current developments of European research in RMDs vis-à-vis other countries and regions, stressing the need for further research and innovation in this field.

The discussion centred on the scope of priority that the work programme attributes to RMDs. While stakeholders expressed their desire that more research resources be allocated to RMD as a distinct disease, the Commission's view was that RMD should only be embedded into the wider framework of chronic diseases in order to reflect societal issues at large.

### **6th Meeting** (22 June 2011)

*"RMDs and Active and Healthy Ageing"*

The aim of the 6<sup>th</sup> meeting of the IG was to present evidence on RMDs as one of the main causes of disability, dependency and inactivity among the elderly, as well as discuss on the need to pay particular attention to these diseases to reduce the negative impact of the ageing of the population. **Dr Kiros Karamanidis** (Institute for Biomechanics and Orthopaedics, German Sport University Cologne) gave an overview on the links between RMDs and ageing. Although RMDs affect people of all ages, he proved that the prevalence of RMDs dramatically increases with ageing. **Marianne van den Berg** (Policy Analyst Innovation for Health and Consumers, DG Health and Consumers, European Commission) presented "The Pilot European Innovation Partnership on Active and Healthy Ageing", which aims at extending the healthy lifespan of Europeans by two years by 2020. Reducing the number of RMD patients will play an important part in this. Other contributions came from **Jacqueline Mäder** (former Chairperson of the EULAR Standing Committee of PARE) and **Stephan Bevan** (Director, The Work Foundation and Founding President of the Fit for Work Europe Coalition) who highlighted the negative impact of RMDs on national workforce productivity and hence social security systems.

### **7th Meeting** (11 October 2011)

*"Social and economic costs of RMDs"*

The meeting discussed the socioeconomic burden of RMDs on European societies. During the event, new evidence on the health and social care costs of RMDs from different Member States was presented that had been collected and analysed by the EUMUSC.NET project. **Prof Loreto Carmona** (EUMUSC.NET project) showed that RMDs are one of the most disabling diseases and the main cause of absenteeism and early retirement among the working population, incurring large direct (health care costs, outpatient and inpatient costs, etc.) and indirect (loss of productivity, etc.) macroeconomic costs on Member States. The enormous burden of RMDs was acknowledged by the Commission, as **Hana Horka** (Policy Officer, DG SANCO,

European Commission) underlined in her speech. However, according to her, RMDs should be embedded in a wider strategy on chronic diseases. To achieve this, the Commission is undertaking a reflection process with results to be presented in 2012. **Brenda O'Brien** (European Agency for Safety and Health at Work, OSHA) agreed on focusing on RMDs as one of the main health problems, presenting the corresponding OSHA report.

Based on these economic impacts, the subsequent discussion reiterated the call for national RMD strategies.

### 8th Meeting (20 March 2012)

*“Towards an EU strategy on chronic diseases: A follow-up of the Council Conclusions on chronic diseases”*

The aim of the meeting was to discuss the EU work on chronic conditions, particularly in regard to the EU reflection process started after the EU Council Conclusions on chronic illness under the Belgian EU Presidency (2010). **Michael Huebel** (Head of Unit C4 “Health Determinants”, DG SANCO, European Commission) reasserted the holistic Commission approach towards chronic diseases, which does not single out specific conditions including RMDs. **Kore Geil** (Health Counsellor, Danish Representation to the EU) briefly presented the Danish Presidency’s strategy on chronic diseases. **Prof. Maxime Dougados** (President of EULAR) presented the EULAR contribution to the EU Reflection Process on RMDs, stressing different recommendations on prevention, health care and research policy initiatives. Presentations by **Birgit Beger** (Secretary-General, Standing Committee of European Doctors), and **Prof. Anthony Woolf** (EUMUSC.NET) stressed a lack of doctors and of preventive strategies by governments as future critical elements.

The discussion reiterated the need for EU policy-makers to devise an EU-wide RMD strategy and action plan given the pertinence of the issue. Action was demanded to treat RMDs as a health concern in its own right to reflect patients’ special needs and not pursue a generic approach. To this end, a standardised and scientifically viable mechanism for EU-wide data collection must be established.

### 9th Meeting (26 June 2012)

*“RMDs and Pain: Facts and Finding”*

**Prof Giustino Varrassi** (former EFIC President) and **Prof. Joop van Griensven** (President, Pain Alliance Europe) introduced the topic of pain as prevalent in European society. **Prof. von Griensven** (President, Pain Alliance Europe) introduced his association’s ‘Roadmap to Action’, which lists political priorities in tackling pain in Europe, including better access to pain management, the implementation of prevention and education programmes, and monitoring the outcomes in pain care. He called on Member States to develop a network of exchanging best practices. **Neil Betteridge** (EULAR Vice-President, representing PARE) emphasised the importance of RMDs as a leading cause of pain, calling for greater RMD prevention efforts for widespread pain relief.

The ensuing discussion highlighted various aspects of pain treatment. Much attention was given to prevention, whereas current policies only cure symptoms. Therefore, focusing research on painkilling drugs is not a sustainable solution.

### 10th Meeting (20 March 2013)

*“The EU post-2014 budget and the future of health research: Redefining priorities, improving effectiveness”*

The meeting focused on the ongoing debate on the EU budget post 2014 and its potential impact on the allocation of funds for research, particularly medical research.

**Johan Ureel** (Head of Unit B1, Multi-Annual Framework, European Commission)

introduced the Commission’s spending proposal for the 2014-2020 financial framework, underlining the need for greater allocation of funds for research.

**Telemachos Telemachou** (Research Counsellor, Permanent Representation of CY to the EU) gave an insight into the upcoming Horizon 2020 programme, in which a special reference to RMD had been adopted. **Stephan Kuster** (Head of Policy Affairs, Science Europe) presented the view of the scientific community on the framework proposal, stressing the need to increase the budget for research and innovation.

**Dr Maria Vidal** (DG Research, Deputy Head of health research, European Commission) specified the Commission’s research initiatives on chronic diseases in Horizon 2020.

**Prof Maurizio Cutolo** (President-Elect, EULAR) presented the priorities that future research should pursue in the field of chronic diseases. **MEP Ivailo Kalfin** presented the EP’s perspective on health research funding, seconding the need for much larger funds by the EU, which lag behind other major powers such as the US and China.

### 11th Meeting (20 June 2013)

*“New Disability Law: Does it help people with chronic diseases?”*

The aim of the meeting was to discuss the EU initiatives on disability, particularly the implementation of the EU Disability Strategy. **Johan ten Geuzendam** (Head of Unit of Persons with Disabilities, DG Justice, European Commission) presented the Commission’s disability policy programmes, consisting of the European Disability Strategy 2010-2020 and the upcoming European Accessibility Act. He stressed the importance of these initiatives, which aim to harmonise national disability policies and bring them in line with the UN Convention of Rights of Persons with Disabilities.

**Ádám Kósa** (MEP, Chair of the EP Interest Group on Disability) presented on the work of the EP Interest Group on Disability. **Rudi Kennes** (Flemish Agency for People with Disability) presented recent legislation by the Flemish Government, introducing the need for government aid to attribute distinct assistance services to people with special disability needs. On this basis, **Dr Roberto Bertollini** (WHO Representative to the EU) stressed that national governments must forge policies of greater inclusion, stressing the need for disabled persons to have access to the tailored care they need.

**Brenda O’Brien** (European Agency for Safety and Health at Work, OSHA) emphasised the need to protect disabled persons in their workplace, to which present EU legislation is only insufficiently suited. **Neil Betteridge** (EULAR Vice-President representing PARE) cast special light on the need of persons with RMDs.

### **12th Meeting** (16 October 2013)

*“New Data Protection Legislation: Consequences for Health Research”*

The meeting focused on the proposal for a new EU Data Protection Regulation that was being discussed at the European Parliament. In particular, it was discussed the amendments proposed by the rapporteur, which would have a negative impact on medical research. **Takis Hadjigeorgiou** (MEP, Vice-Chair Interest Group) and **Thomas Zerdick** (Head of Data Protection Reform, DG Justice, European Commission) introduced the new EU Data Protection Regulation (DPR). On this basis, **Dr Bonnie Wolff-Boenisch** (Head of Research Affairs, Science Europe) and **Nick Meade** (Patients Network for Medical Research and Health) presented how aspects of tightened data protection standards harm research that is crucial to medical research on RMD treatment. The reform neglects basic foundations of the conduct of social research on which patients depend. **Antoine Fobe** (EU and Int'l Affairs Unit, CNIL), on the contrary, defended tightened data protection standards.

### **13<sup>th</sup> Meeting** (18 March 2014)

*“What EU Public Health Policies for 2014-2019?: The EU contribution to public health in recent years and the challenges for the next Parliamentary and Commission terms”*

The aim of the meeting was to assess the EU interventions in the public health domain during the current Commission and Parliamentary terms as well as to outline the main challenges and working lines for the coming years. **Sylvain Giraud** (Head of Unit Health Strategy and International, European Commission) presented the main working lines and achievement of the European Commission, in particularly those implemented by DG SANCO. **Lukas Goergiou** (Attaché for Public Health and Pharmaceuticals, Permanent Representation of Cyprus to the EU) presented the Cypriot perspective with regard to the relevance of EU policies in his country. He particularly addressed the Cyprus Strategy on RMDs. The presentation of **Kai Michelsen** (University of Maastricht) particularly addressed the value of EU public health policies, highlighting the important contribution of the EU to improving the health of EU citizens. He also pointed out some pending challenges the EU should focus on the coming years. **Neil Betteridge** (EULAR, International Liaison Officer, Public Affairs) presented the RMD community perspective. He pointed out that the EU has only recently started to acknowledge the relevance of RMD, which implies a more positive perspective for the RMD community. He also presented some recommendations to the EU for the reduction of the enormous burden of RMDs and other chronic conditions. Finally, **Sören Haar** (EULAR Brussels Office, Manager) presented the activities and results of the IG from 2009 to 2014.