EULAR directory of PARE organisations 2017/2018
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About “EULAR directory of PARE organisations”
One of the priorities of EULAR is to strengthen the network of member organisations. This directory is a tool to increase the level of knowledge of PARE (People with Arthritis/Rheumatism in Europe) organisations about each other.

The data provided by the directory serves as a tool for EULAR and its organisations with common aims and objectives to be able to help and learn from each other.

EULAR would like to thank Maria Batziou (Greece), Diana Skingle (United Kingdom), Nele Caeyers (Belgium), Sandra Canadelo (Portugal), Alison Kent (United Kingdom) and Jacqueline Mäder (Switzerland), for their support and commitment to develop this directory and we are sure that this publication helps to make a difference and overcome national boundaries and facilitates mutual learning.

About EULAR
The European League Against Rheumatism (EULAR) is the organisation which represents the patient, health professional and scientific societies of rheumatology of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic and musculoskeletal diseases. Within EULAR, national PARE organisations work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org

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Publisher EULAR Standing Committee of People with Arthritis/Rheumatism in Europe
Österreichische Rheumaliga
Austrian League Against Rheumatism

Address of the organisation

<table>
<thead>
<tr>
<th>Street</th>
<th>Dorfstrasse 4, Maria Alm</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town</td>
<td>Salzburg</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>5721</td>
</tr>
<tr>
<td>Country</td>
<td>Austria</td>
</tr>
<tr>
<td>Tel</td>
<td>0043 699 155 416 79</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:info@rheumaliga.at">info@rheumaliga.at</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.rheumaliga.at">www.rheumaliga.at</a></td>
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</table>

Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President</th>
<th>Gertraud Schaffer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer</td>
<td>Roswitha Ben Hassen</td>
</tr>
</tbody>
</table>

Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name</th>
<th>Nicola Lins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:nicil@aon.at">nicil@aon.at</a></td>
</tr>
<tr>
<td>Tel</td>
<td>0043 699 171 889 89</td>
</tr>
</tbody>
</table>

Youth activities

10 members of parents with kids that suffer from RMDs

<table>
<thead>
<tr>
<th>Contact</th>
<th>Karin Formanek</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:shg_rheumalis@yahoo.com">shg_rheumalis@yahoo.com</a></td>
</tr>
<tr>
<td>Tel</td>
<td>0043 699 197 488 11</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.rheumalis.org">http://www.rheumalis.org</a></td>
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</table>

About the organisation

Österreichische Rheumaliga was founded in 1995

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Patient information and support services
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients

All types of RMDs are represented. The organisation has 8 branches and 15 local groups, covering some areas of the country and it is run by volunteers with RMDs.

Activities & Programmes

- Educational activities with health professionals about several topics like treatments-diets-exercise
- Organised a meeting once per year for raising awareness to the public about RMDs
- Organised a sport year once per year to introduce different sports in relation to RMDs
**ReumaNet vzw.**  
Belgian League Against Rheumatism (Flanders)

### Address of the organisation

<table>
<thead>
<tr>
<th>Street</th>
<th>Bresserdijk 75</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town</td>
<td>Mol</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>BE – 2400</td>
</tr>
<tr>
<td>Country</td>
<td>Belgium</td>
</tr>
<tr>
<td>Tel</td>
<td>0032 143 223 99</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:info@reumanet.be">info@reumanet.be</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.reumanet.be">www.reumanet.be</a></td>
</tr>
</tbody>
</table>

### Name and title of President, Treasurer and General Manager/Secretary

- **President:** Gerd Jacobs  
- **Treasurer:** Ilse De Keyser  
- **General Manager/Secretary:** Nele Caeyers

### Liaison person with EULAR

- **Name:** Nele Caeyers  
- **Email:** nele@ReumaNet.be  
- **Tel:** 0032 143 223 99

### About the organisation

**Aims:**
- Raise awareness about RMD’s  
- Improve the quality of life for people with RMD’s  
- Increase collaboration between different patient organisations  
- Increase collaboration with different stakeholders and policy makers

ReumaNet has started working with two part time staff members in 2011. They are supported by a large group of volunteers.

There are regional and local branches covering the Flemish part of the country. In total the organisation is comprised of 5 member organisations and 3 working groups, which stand for about 5000 individual members.
ReumaNet vzw.
Belgian League Against Rheumatism (Flanders)

Activities & Programmes
Since ReumaNet has two part time staff, the organisation has become more professional. The main activities at the moment are:

• World Arthritis Day
• Patient Research Partner Project
• ReumaMaMa’s: project for parents with a child with an RMD and future parents to be with an RMD.
• Special website for children, youth and their parents/teachers...
• ReumaNet is currently working on a creating a Patient Expertise Center for Rheumatology.

Youth activities
Age groups represented: 18–35
Contact: Nele Caeyers
Email: Nele@reumanet.be
Tel/Skype: +32 498 32 03 05, nelecaeyers
Website: www.reumanet.be
Facebook/Twitter: ReumaNet

Youth Organisation & Structure
ORKA: Group for parents with a child with RMD.

Youth Activities & Programmes
• They organise diverse activities in which also youth takes part.
• The youth group also meets irregularly, on a personal basis.
• Summer camp
• Trips to zoo, picnic, sea...
• BBQ
• Personal meetings
www.ikhebreuma.be: website specially developed for children, youth and their parents/teachers/youth leaders...
# CLAIR - Confédération de Lutte contre les Affections Inflammatoires Rhumatismales
Belgian League Against Rheumatism (Wallonia)

## Address of the organisation

<table>
<thead>
<tr>
<th>Street</th>
<th>Rue Chauny 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town</td>
<td>Templeuve</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>BE – 7520</td>
</tr>
<tr>
<td>Country</td>
<td>Belgium</td>
</tr>
<tr>
<td>Tel</td>
<td>0032 494 151 6</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:info@clair.be">info@clair.be</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.clair.be">www.clair.be</a></td>
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## Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President</th>
<th>Bernadette Vanleeuw</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer</td>
<td>Paul Hankart</td>
</tr>
<tr>
<td>General Manager/Secretary</td>
<td>Guy Dagnies</td>
</tr>
</tbody>
</table>

## About the organisation

**CLAIR was founded in 2004**

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients

The types of RMDs that are represented by the organisation are the following: Rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile arthritis, lupus (SLE) and scleroderma.

The organisation has regional and local branches which cover the French speaking part of the country and they are run by volunteers with RMDs. The total number of members is about 2500 individuals.
### CLAIR - Confédération de Lutte contre les Affections Inflammatoires Rhumatismales
Belgian League Against Rheumatism (Wallonia)

<table>
<thead>
<tr>
<th>Activities &amp; Programmes</th>
<th>Youth activities</th>
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<tr>
<td>One of the largest recent campaigns was <em>The national journey for arthritis.</em></td>
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<tr>
<td>The most important topics for the organisation in the coming years are:</td>
<td></td>
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<tr>
<td>• Raising awareness about RMDs</td>
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</tr>
<tr>
<td>• Motivating new volunteers</td>
<td>No youth activities at present.</td>
</tr>
</tbody>
</table>
**BOPRD**

Bulgarian Organisation for Patients with Rheumatic Diseases

### Address of the organisation

- **Street:** Dianabad 9-5-20
- **City/Town:** Sofia
- **ZIP/Postal Code:** BG – 1172
- **Country:** Republic of Bulgaria
- **Tel:** 0035 989 840 143 9
- **Email:** revmatologia.org@gmail.com
- **Website:** www.revmatologia.org

### Name and title of President, Treasurer and General Manager/Secretary

- **President:** Tzveta Apostolova
- **Treasurer:** Latinka Stancheva
- **General Manager/Secretary:** Boryana Boteva

### Liaison person with EULAR

- **Name:** Boryana Boteva
- **Email:** revmatologia.org@gmail.com
- **Tel:** 0035 989 840 143 9

### About the organisation

**BOPRD was founded in 2010**

The aims of the organisation are:

- Raising awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaigns for equal rights and treatment
- Improve the quality of life of people with RMD’s
- Access to healthcare and newest medicines

All types of RMD’s are represented by the organisation. The organisation has local branches in every municipality of the country and they are run by volunteers with RMDs. The organisation counts approximately 300 individual members.
BOPRD
Bulgarian Organisation for Patients with Rheumatic Diseases

<table>
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<tr>
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<tr>
<td>• Raising awareness about RMD's</td>
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<tr>
<td>• Establishing groups for children and parents</td>
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<tr>
<td>• Education for people with RMD’s</td>
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<tr>
<td>• Good communication with politicians and lobbying</td>
</tr>
<tr>
<td>• Establishing self management courses for people with RMD’s</td>
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<table>
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<tr>
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<td>No youth activities at present.</td>
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### HRVATSKA
#### Liga Protiv Reumatizma Croatian League Against Rheumatism

#### Address of the organisation

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<tr>
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<td>ZIP/Postal Code:</td>
<td>Hr – 10000</td>
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<tr>
<td>Tel:</td>
<td>+385 (0) 137 872 48</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:franegrubisic@gmail.com">franegrubisic@gmail.com</a></td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.reuma.hr">www.reuma.hr</a></td>
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#### Name and title of President, Treasurer and General Manager/Secretary

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<tbody>
<tr>
<td>President</td>
<td>Frane Grubišić</td>
</tr>
<tr>
<td>Treasurer</td>
<td>Želimir Vukosav</td>
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#### Liaison person with EULAR

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Name:</td>
<td>Frane Grubišić</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:franegrubisic@gmail.com">franegrubisic@gmail.com</a></td>
</tr>
<tr>
<td>Tel:</td>
<td>+385 (0) 137 872 48</td>
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</table>

#### About the organisation

**Hrvatska liga Protiv reumatizma was founded in 1992**

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Connecting medical experts and people with RMDs
- Provide information and education

All inflammatory, degenerative, metabolic and extraarticular RMDs including scleroderma are represented by the organisation. The organisation has regional and local branches covering the whole country.

There is no paid staff working for the organisation at present. People with RMDs and health professionals are on the board. The organisation has more than 5500 individual members, most of them patients.
HRVATSKA
Liga Protiv Reumatizma Croatian League Against Rheumatism

Activities & Programmes

Twenty-six educational booklets were published, while official journal “Reuma” is published regularly, twice a year. One of the largest recent campaigns was the promotion of the EULAR Charter for Work in the parliament and throughout the country. Apart from regular activities (lectures, round-tables) public actions are especially intensive during Bone and Joint Decade World Days.

The most important topics for the organisation in the coming years are:

Financial issues - partnership with companies and state institutions

- Participation in international and European scientific events in the field of rheumatology
- Raising awareness about RMDs
- Establishing a network of volunteers to carry out projects
- Providing facilities for rehabilitation and medical and other devices (wheelchairs, orthoses) to the members of the organisation who need them without charge.

Youth Organisation & Structure

No youth activities at present
Anti-rheumatikos Syndesmos Kyprou
CYPLAR – Cyprus League Against Rheumatism

Address of the organisation

Street: Onisillou 16
City/Town: Aglantzia / Nicosia
ZIP/Postal Code: CY – 2121
Country: Cyprus
Tel: 0035 722 428 285
Email: cyplar@cytanet.com.cy
Website: www.rheumatism.org.cy

Name and title of President, Treasurer and General Manager/Secretary

President: Marios Kouloumas
Treasurer: Despo Charalambous
General Manager/Secretary: Andri Phoka

Liaison person with EULAR

Name: Marios Kouloumas
Email: Kouloumas.rn@cytanet.com.cy
Tel: +357 99463533

About the organisation

The aims of the organisation are:
1. The provision of the suitable medical treatment and support to Cypriot patients, with the immediate planning and enforcement of a National Strategic Plan
2. The factual recognition of the seriousness and dimensions of rheumatism
3. The immediate establishment of the first Multidimensional State Rheumatic Clinic and rheumatic centres at all State Hospitals.
4. The establishment of well equipped Rehabilitation Centres
5. The conduct of scientific studies and epidemiological research as well as the creation of archives
6. The enforcement of programmes for social support, information and training of Cypriot rheumatic patients
7. The creation of State Centres for relief care as well as home care services
8. Cooperation with authorities, organisation, foundations and people in Cyprus and abroad for the promotion of the above goals.
9. Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
10. Campaign for equal rights and treatment
11. Improve the quality of life for people with RMDs
12. Educate and empower the people with RMDs

The organisation is run by a board of 21 members and has local branches in the three main cities of the country. Also it is run by 1 CEO who is a volunteer, 3 full time and 3 part time paid staff and 154 volunteers. In total the organisation has about 4450 individual members.

The League is a voluntary, charitable and non-profit organisation for people with RMDs and thus all the members of the board are volunteers and receive no monetary gain. The board members are elected every three years.

CYPLAR was founded in 1984

By a small group of rheumatic patients for the provision of the suitable medical treatment and support to Cypriot patients, so as to ensure in every way, their right for a good standard of living with quality, dignity and respect from all.
### About the organisation

All the members of the Executive Committee must be people with RMDs.

The main aim of the organisation is to implement the National Action plan of RMDs and the sustainability of the programmes and services of the league to the people with RMDs.

### Activities & Programmes

One of the largest recent campaigns was the access to treatments regarding the protocols for the biologics, and the right of the doctors in partnership with the patients to decide about the most effective treatment.

Another significant achievement is the involvement of the patient representatives at the designing, implementing, monitoring and evaluating the new healthcare system.

#### Awareness activities

- Annual Awareness Week for the Rheumatic and Musculoskeletal Diseases – 2nd week of May
- World Arthritis Day – 12th of October
- World Lupus Day – 10th of May
- Annual Awareness Day for Ankylosing Spondylitis – every first Saturday of May
- World Fibromyalgia Day – 12th May
- World Scleroderma Day – 29th of June

#### Fundraising events

- Christmas Tea in Nicosia,
- Happy afternoon in Larnaka, Limassol and Paphos
- Theatrical Show in Nicosia and Limassol
- Festival and Fair of the Cyplar

#### Programmes

- Psychosocial Support
- Creation and Support Centre

### Activities & Programmes (continued)

#### Volunteer’s Body

- Information, Prevention Programme and Educating Programme
- Youth project
- RMDs and Work
- Rehabilitation services & home care
- Exercise groups
- Fundraising events

### Youth activities

- **Age groups represented:** 18–35
- **Contact:** Antri Phoka
- **Email:** andri.phoka@gmail.com
- **Tel:** +35799789223
- **Website:** www.rheumatism.org
- **Facebook/Twitter:** cyprus league against rheumatism/cyplar

### Youth Organisation & Structure

All the members of the league at the age group 18–35 consist the youth group working under the hat of the Cyplar. There is a leader and a steering group of 3 to 5 people who discuss and plan the activities and the programmes aiming at the youth with RMDs.

### Youth Activities & Programmes

- Educational workshops
- Self management programmes
- Support groups
- Social events
# Revma Liga v ČR

**Czech League**

## Address of the organisation

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Street:</td>
<td>Na slupi 4</td>
</tr>
<tr>
<td>City/Town:</td>
<td>Prague</td>
</tr>
<tr>
<td>ZIP/Postal Code:</td>
<td>CZ – 12850 Prague</td>
</tr>
<tr>
<td>Country:</td>
<td>Czech Republic</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:revmaliga@email.cz">revmaliga@email.cz</a></td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.revmaliga.cz">www.revmaliga.cz</a></td>
</tr>
</tbody>
</table>

## Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>President</td>
<td>Edita Müllerová</td>
</tr>
<tr>
<td>Treasurer</td>
<td>Věra Matějková</td>
</tr>
<tr>
<td>General Manager/Secretary</td>
<td>Věra Matějková</td>
</tr>
</tbody>
</table>

## Liaison person with EULAR

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Hana Šmucrová</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:smucrova.hana@gmail.com">smucrova.hana@gmail.com</a></td>
</tr>
<tr>
<td>Tel</td>
<td>00420 731 070 445</td>
</tr>
</tbody>
</table>

## About the organisation

**Revma liga v ČR was founded in 1991**

The aims of the organisation are:

- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients
- Provide patient education
- Enable easy access to physiotherapy for people with RMDs

The types of RMDs that are represented by the organisation are the following: rheumatoid arthritis, ankylosing spondylitis, juvenile arthritis, osteoarthritis, lupus (SLE) and scleroderma. The organisation has 6 local branches which are run by volunteers with RMDs. In total the organisations counts 460 individual members.
Revma Liga v ČR
Czech League

Activities & Programmes

- Publishing a paper members’ magazine
- Maintaining an active life in regional clubs (rehabilitation services, social events for members)
- Raising public awareness about RMDs

Skills we would like to improve:
- How to recruit more volunteers
- How to win more active members for our organisation
- How to win young members

Youth Organisation & Structure

No youth activities at present
Gigtforeningen
The Danish Rheumatism Association

Address of the organisation

- Street: Gentoftegade 118
- City/Town: Gentofte
- ZIP/Postal Code: DK – 2820
- Country: Denmark
- Tel: +45 (0) 397 780 00
- Email: info@gigtforeningen.dk
- Website: www.gigtforeningen.dk

Name and title of President, Treasurer and General Manager/Secretary

- President: Ulrik Bülow
- Treasurer:
- General Manager/Secretary: Mette Bryde Lind

Liaison person with EULAR

- Name: Connie Ziegler
- Email: cziegler@gigtforeningen.dk
- Tel: +45 (0) 397 780 38

About the organisation

The Danish rheumatism association was founded in 1936

The organisation has 78,800 members with about 500 active volunteers in 22 local constituencies across the country.

Over the past 10 years the Danish Rheumatism Association has supported research in RMDs with more than DKK 100 million. This means that a substantial part of the non-commercial rheumatology research in Denmark is being funded by the Association. Through extensive outreach campaigns and concrete activities, the association utilizes the scientific achievements for the benefit of people living with a rheumatic disease.
Gigtforeningen
The Danish Rheumatism Association

Activities & Programmes

Patient support is a very important concern. We provide financial support for patients with special needs, and each year our free hotline advice service answers around 7,000 inquiries from people who need professional support on the physical, mental, social and legal issues that come with an RMD.

The daily contact with people who have to live with the consequences of a chronic disease is also of great importance for our political activities. It is to a large extent through this contact that we become aware of health-related, social and other issues to be addressed by decision-makers.

Furthermore, the association owns and operates a hospital specialising in rheumatic diseases, as well as three health and training centres (SANO).

Youth activities

Age groups represented: 12-36
Contact: Rikke Dieu Larsen
Email: fnug@fnug.dk
Tel/Skype: 0045 418 195 45
Website: www.fnug.dk
Facebook/Twitter: www.facebook.com groups/5480902035

Youth Organisation & Structure

There is an independent youth organisation comprising 100-500 members for 12-36 year olds, offering members meetings, lectures, social activities, weekend seminars, etc.
# Eesti Reumaliit
Estonian Rheumatism Association

## Address of the organisation

<table>
<thead>
<tr>
<th>Street:</th>
<th>Toompuiestee 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town:</td>
<td>Tallinn</td>
</tr>
<tr>
<td>ZIP/Postal Code:</td>
<td>10137</td>
</tr>
<tr>
<td>Country:</td>
<td>Estonia</td>
</tr>
<tr>
<td>Tel:</td>
<td>+372 5343 5501</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:info@reumaliit.ee">info@reumaliit.ee</a></td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.reumaliit.ee">www.reumaliit.ee</a></td>
</tr>
</tbody>
</table>

## Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President:</th>
<th>Terje Karp</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer:</td>
<td>Marek Jaakson</td>
</tr>
<tr>
<td>General Manager/</td>
<td>Marek Jaakson</td>
</tr>
<tr>
<td>Secretary:</td>
<td>Secretary: Marek Jaakson</td>
</tr>
</tbody>
</table>

## Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name:</th>
<th>Marek Jaakson</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email:</td>
<td><a href="mailto:marek@reumaliit.ee">marek@reumaliit.ee</a></td>
</tr>
<tr>
<td>Tel:</td>
<td>+372 584 555 52</td>
</tr>
</tbody>
</table>

## About the organisation

The aims of the organisation are:

- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment!
- Improve the quality of life for people with RMDs!
- Promote contacts with fellow patients!
- Improve co-operation between patients and health care professionals

All types of RMDs are represented by the organisation, which has 9 local branches covering the whole country and two disease specific organisations; Estonian Osteoporosis Association and Children Association. The branches are run by volunteers with RMDs, supported by 6 halftime and 2 full-time staff members in the headquarter.
# Eesti Reumaliit
Estonian Rheumatism Association

## Activities & Programmes

During the year 2015 we are planning to organise an our traditional events:

- **In March**
  - Rehabilitation Conference

- **In May**
  - Rheumaforum

- **In June**
  - Development Workshop

- **In August**
  - Nordic Walking Day

Also we take part in EULAR activities and events as CEO meetings, EULAR Annual European Conference of PARE, EULAR Annual Congress of Rheumatology, etc.

## Youth activities

- **Age groups represented:** 15–30
- **Contact:** Jonas Grauberg
- **Email:** jonas@reumaliit.ee
- **Tel/Skype:** +372 555 67 144

## Youth Organisation & Structure

It is set up as a group under Estonian Rheumatism Association’s executive team to save youth group’s members from paperwork that comes with founding/running a non-profit organisation. The group has two regional coordinators: one for North-Estonia and the capital and the other for South-Estonia.

## Youth Activities & Programmes

In 2015 we are planning to organise an event/workshop every 3 months and a summer camp.

The youth group coordinators are also visiting different schools in Estonia as part of project named “From Youth to Youth” to inform 14-15 year-old pupils about RMDs.
Suomen Reumaliitto Ry
The Finnish Rheumatism Association

Address of the organisation

- **Street:** Iso Roobertinkatu 20 – 22 A
- **City/Town:** Helsinki
- **ZIP/Postal Code:** 00120
- **Country:** Finland
- **Tel:** 0035 894 761 55
- **Email:** info@reumaliitto.fi
- **Website:** www.reumaliitto.fi

Name and title of President, Treasurer and General Manager/Secretary

- **President:** Satu Gustafsson
- **Treasurer:** Evita Salo
- **General Manager/Secretary:** Maria Ekroth

About the organisation

**Suomen Reumaliitto Ry was founded in 1947**

The aims of the organisation are:
- **Raise awareness** about rheumatic and musculoskeletal diseases (RMDs)
- **Campaign for equal rights and treatment**
- **Improve the quality of life** for people with RMDs
- **Promote contacts** with fellow patients
- **Improve co-operation** between patients and health care professionals

All types of RMDs are represented by the organisation, which has 164 local branches covering the whole country. The branches are run by volunteers with RMDs, supported by 19 staff members in the headquarter.

The organisation has around 45,000 individual members.
Suomen Reumaliitto Ry
The Finnish Rheumatism Association

Activities & Programmes

The Association’s national exercise campaigns, like the occupational health day Keltaisen nauhan päävää (Yellow ribbon day), Tule-huoltamo (Musculoskeletal Service Station), providing visitors with functioning capacity tests of musculoskeletal system and fitness exercise guidance, and Veshumppa, a form of aquatic sport, have all remained popular throughout the years.

During 2015 and 2016 The Finnish Rheumatism Association with its local member associations and other partners will lead a campaign called Well-being through motion. The campaign’s main objective is to encourage and educate everyone (those with RMDs, members of the Association and the wider audience) on the benefits of an active lifestyle and on caring for your well-being.

Other important goals for the next two years are to:

- Encourage young doctors to specialize in rheumatology (Reumatologikampanja)
- Publish updated information on RMDs to patients, health care professionals, as well as the general public on multiple platforms (internet, print, media, and video)
- Further support young people, parents, and children with RMDs
- Succeed an early diagnosis and provide support

Youth activities

Age groups represented: 10–35
Contact: Sini Hirvonen
Email: sini.hirvonen@reumaliitto.fi
Tel: 0035 844 563 008 0

Youth Organisation & Structure

Activities for kids/youth (10–17 yrs) are organised by the Finnish Rheumatism Association.
Contact person: Sini Hirvonen, sini.hirvonen@reumaliitto.fi

Finnish Young Rheumatics (FYR): National Association for Young People (18–35 yrs).
Contact person: Emmi Myöhänen, emmi.myohanen@suomenreumanuoret.fi

The association is a member organisation of the Finnish Rheumatism Association.

Youth Activities & Programmes

- Youth CAMP 8. – 9.5.2015
  A camp for youth (15–18 yrs) facing transition in the following year.
- Rehabilitation camps for kids (10–15 yrs) in Southern Europe.
- Peer support meetings for youth (18–35 yrs) organised by FYR.
NORA –
Non-governmental Organisation for Rheumatism & Arthritis

Address of the organisation

Street: Blagoj Davkov 18/B1
City/Town: Skopje
ZIP/Postal Code: 1000
Country: Republic of Macedonia
Tel: 00389 2 321 4365
Email: office@nora.mk
Website: www.nora.mk

Name and title of President, Treasurer and General Manager/Secretary

President: Dragan Chichikj
Treasurer: Senka Naumovska
Honorary President: Dragan Chichikj – GM
Programme Coordinator: Irina Hadji Mitova

Liaison person with EULAR

Name: Irina Hadji Mitova & Dragan Chichikj
Email: office@nora.mk
Tel: 00389 2 321 4365

About the organisation

NORA was founded in January 2008
The main aims of the organisation are:
• to raise awareness about rheumatic and musculoskeletal diseases (RMDs)
• to campaign for equal rights and treatment
• to improve the quality of life for people with RMDs
• to enable the access of modern medical treatment in the state
• to promote contacts with fellow patients
• to educate people with RMDs
• to conduct research on various subjects which concern patients with RMDs

NORA represents every type of RMD, with an accent on: Rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile idiopathic arthritis, lupus (SLE), scleroderma and vasculitis. The headquarters is in Skopje, and it is run by 2-4 paid staff members and 1-2 volunteers. In early 2013 we’ve changed our location so that we are easily accessible for people with additional needs and in order to have the opportunity to do workshops and seminars in our own facilities. NORA’s membership is growing on a daily basis, and currently we have 1009 members.

Since its establishment, NORA has done many pioneering activities and campaigns, and we are very often seen as the leading organisation that sets the criteria for proper management of a patient organisation.
**NORA – Non-governmental Organisation for Rheumatism & Arthritis**

**Activities & Programmes**

NORA’s main activities are the following:
- Improving the health care standards in the whole country through close cooperation with relevant institutions
- Educating patients with RMDs and health professionals
- Raising public awareness about RMDs
- Combating unequal treatment in society for patients with RMDs

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**Youth activities**

<table>
<thead>
<tr>
<th>Age groups represented:</th>
<th>15–24</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact:</td>
<td>Irina Hadji Mitova</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:office@nora.mk">office@nora.mk</a></td>
</tr>
<tr>
<td>Tel/Skype:</td>
<td>00389 70 989 278</td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.nora.mk">www.nora.mk</a></td>
</tr>
<tr>
<td>Facebook/Twitter:</td>
<td>NGO NORA/ @ngoNORAA</td>
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</tbody>
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**Youth Organisation & Structure**

We have limited youth activities. Some are dedicated, and some are in development.

The organisation and structure of the youth activities is comprised by selected members.

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**Youth Activities & Programmes**

In development
AFLAR - Association Française de Lutte Anti-Rhumatismale
French League Against Rheumatism

About the organisation

AFLAR was founded in 1928

The main objectives of the organisation are:

- Raise general awareness to inform about the impacts of such diseases beyond clichés
- Inform about RMDs, their care, their prevention and medical research
- Improve the quality of care by transmitting savoir-faire and ensuring health professionals training
- Help patients live better with the disease and be part of the healthcare process
- Educate patients on how to manage their disease and how to be involved in the planning of health policies
- Equal access to care for every RMD patient
- Make governments and decision-makers fully understand and realise the human, social and economical weight of RMDs
- Improve social care and the resources for prevention and research

All types of RMDs, all types of treatments, all categories of professionals and institutions are included and represented by the organisation. Several specialised patient associations are affiliated to AFLAR. AFLAR is thus transversal and multidisciplinary. The total number of members, supporters and affiliated association members is about 6500 individuals. Membership is not a prerequisite and everyone can have access to AFLAR’s services.
AFLAR - Association Française de Lutte Anti-Rhumatismale
French League Against Rheumatism

Activities & Programmes

One of the largest recent campaigns was against Osteoporosis (www.pourdesosplusfort.org) with the IOF Foundation and Osteoarthritis (www.stop-arthrose.org).

Plans for 2015:
- Developing the first Osteoarthritis National Statement
- Development of a web youth group platform and a French training programme for employer based on the EULAR Charter for work
- An Annual congress for patients and health professionnals in December 2015

Youth activities

Age groups represented: 18–35
Contact: Jean-Noël Dachicourt
Email: jeannoel.dachicourt@aflar.org
Tel/Skype: djinoworld
Facebook/Twitter: @asso_aflar

Youth Organisation & Structure

Youth organisation is in creation.

Youth Activities & Programmes

- Health Education workshops
- Informal weekend meetings
- Online Forums for youth organised
Deutsche Rheuma-Liga Bundesverband e.V.
German League Against Rheumatism and Arthritis

Address of the organisation

Street: Maximilianstrasse 14
City/Town: Bonn
ZIP/Postal Code: DE – 53111
Country: Germany
Tel: 0049 228 766 060
Email: bv@rheuma-liga.de
Website: www.rheuma-liga.de

Name and title of President, Treasurer and General Manager/Secretary

President: Prof. Dr. med. Erika Gromnica-Ihle
Treasurer: Claus Heckmann
General Manager/Secretary: Ursula Faubel

Liaison person with EULAR

Name: Ursula Faubel
Email: bv.faubel@rheuma-liga.de
Tel: 0049 228 766 060

About the organisation

Deutsche Rheuma-Liga Bundesverband e.V. was founded in 1970

The overall aim of the organisation is to improve the situation of people with arthritis and rheumatism. The organisation achieves this goal by:

- Supporting the member organisations in organizing self-help activities and services for people with arthritis
- Raising awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaigning for the improvement of medical treatment, psychological and social support
- Stimulating and supporting research

All forms of RMDs are represented by the organisation. The organisation has 16 regional (Länder-) organisations which cover the whole country and three nationwide working member organisations for people with ankylosing spondylitis, lupus erythematosus and scleroderma. In total Deutsche Rheuma-Liga has more than 280,000 individual members.
### Deutsche Rheuma-Liga Bundesverband e.V.
German League Against Rheumatism and Arthritis

**Activities & Programmes**

**Skills the organisation could teach:**
We provide information about our activities and we are gladly willing to share our know-how about organising self-help and services for people with arthritis, about our campaigning and awareness-raising. We have people with different expertise within the staff and volunteers of our organisation.

**Skills the organisation would like to improve:**
We are interested in learning from other organisations about fundraising and ways to promote self-management, about new ways of reaching out to people with arthritis of different age groups and background, about campaigning and awareness-raising.

In 2014 a four-year campaign “independent living-changing society” was started in order to inform the public about the ways people with arthritis manage their lives with the condition and participate in different aspects of life. Each year there will be a different focus: daily living, changing society, shaping the future, involving politics.

**Youth activities**

<table>
<thead>
<tr>
<th>Age groups represented:</th>
<th>Up to 35 years old</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact:</td>
<td>Monika Mayer</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:bv.mayer@rheuma-liga.de">bv.mayer@rheuma-liga.de</a></td>
</tr>
<tr>
<td>Tel/Skype:</td>
<td>0049 228 766 062 2</td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://geton.rheuma-liga.de/">http://geton.rheuma-liga.de/</a></td>
</tr>
<tr>
<td>Facebook:</td>
<td><a href="http://www.facebook.com/DeutscheRheumaLiga">www.facebook.com/DeutscheRheumaLiga</a></td>
</tr>
</tbody>
</table>

**Youth Organisation & Structure**

100–500 members for
1) Young people up to 35 years
2) Parents with children

**Youth Activities & Programmes**

Meetings, workshops and seminars on regional and national level, awareness-raising events, political lobbying with action plan for children and young people with arthritis, website, Facebook, Internet forums.
E.L.E.A.N.A.
Hellenic League Against Rheumatism

Address of the organisation

Street: Kipselis 2
City/Town: Athens
ZIP/Postal Code: 11362
Country: Greece – Hellas
Tel: 0030 210 823 730 2
Email: info@arthritis.org.gr
Website: www.arthritis.org.gr

Name and title of President, Treasurer and General Manager/Secretary

President: Athanasia Pappa
Treasurer: Theodora Papastavrou
General Manager/Secretary: Theodora Seitanidou
Other: Christalla Karaisaridou

Liaison person with EULAR

Name: Theodora Seitanidou
Email: dodi_812@yahoo.gr
Tel: 0030 6977062360

About the organisation

EΛEANA was founded in 1978
The aims of the organisation are:
• Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
• Improve the quality of life for people with RMDs
• Campaign for equal rights and treatment
• Promote contact with fellow patients

Activities & Programmes

Large recent campaigns included:
• Operating the Psychological Support Hotline for People with RMDs for the eighth consecutive year so far
• Coordinating two psychological support teams on a weekly base
• Organizing the annual Walkathon for People with RMDs in collaboration with the Dodecanesian Association of Autoimmune Rheumatic Diseases
• Presenting Ms. Athanasia Pappa’s children’s book, which is entitled “My friend NIAPA” and discusses her personal experiences on growing up with an RMD. Our upcoming goal is to communicate this book to schools across Greece and raise children’s awareness towards children dealing with an RMD
• Organizing several workshops about physical therapy, photography, cosmetics manufacturing, ikebana
• Annual greek meeting for people with RMDs
E.E.A.N.A.
Hellenic League Against Rheumatism

Activities & Programmes (continued)

- Councelling seminars with nurses for people with RMDs
- Putting together Christmas Bazaars in Athens and Patras and selling handmade products made from our members in order to increase our financial resources

Youth Activities & Programmes

In order to increase the participation of young people we organise activities, respecting our members diversity, designed to involve more youngsters:

- Picnics and exercises while having fun at the Veikou Park in Athens
- Yoga classes
- Arranging lower prices for members of our organisation at the ETHNIC FITNESS CLUB gym promoting the physical improvement of our members
- “Walk for Life and Hope”, a campaign for promoting peoples physical and mental wellbeing and raise awareness for people suffering from RMDs
- Support groups offering emotional and psychological support from our psychologist
- Photography seminars
- Kids Camp in August for children with RMDs
- Cooking seminars entitled “I live happily in the kitchen”, created in order to offer practical solutions and advice to people suffering from RA

Youth activities

Age groups represented:
Underage and youth (aged 18 to 35)
Contact: Theodora Papastavrou
Email: doritsa.ny@gmail.com
Tel/Skype: 0030 6946571229

Youth Organisation & Structure

Part of the board of Directors of Hellenic League Against Rheumatism.

Aiming to bring a youth perspective, we try to engage young people to voice their ideas and concerns, their experiences and suggestions in order to create a positive change. To observe how young people in Europe are fighting against RMDs and for equal rights and opportunities. We try to find out our members interests and availability, through personal conversations and questionnaires. Who and how they are willing to participate in concrete youth activities.
Magyar Reumabetegek Egyesülete
Hungarian League of Patients with Rheumatic Diseases

Address of the organisation

<table>
<thead>
<tr>
<th>Street</th>
<th>Ürömi utca 56</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town</td>
<td>Budapest</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>Hu 10 23</td>
</tr>
<tr>
<td>Country</td>
<td>Hungary</td>
</tr>
<tr>
<td>Tel</td>
<td>0036 132 633 96</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:ortutay.judit@t-online.hu">ortutay.judit@t-online.hu</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.izuletibetegsegek.hu">www.izuletibetegsegek.hu</a></td>
</tr>
</tbody>
</table>

Name and title of President, Treasurer and General Manager/Secretary

| President         | Dr. Judit Ortutay                   |
| General Manager/Secretary | Dr. Sándor Majtényi                  |

Liaison person with EULAR

| Name              | Judit Ortutay                        |
| Email             | ortutayj@t-online.hu                 |
| Tel               | +36 30 850 6620                       |

About the organisation

Magyar reumabetegek Egyesülete was founded in 1998

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients
- Expand the organisation and to establish regional branches
- Promote education and self-management

The types of RMDs that are represented by the organisation are the following: Rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile arthritis, lupus (SLE), scleroderma, osteoporosis, osteoarthritis. The organisation has 26 member organisations either disease specific or regional and these are run by volunteers.
Magyar Reumabetegek Egyesülete
Hungarian League of Patients with Rheumatic Diseases

Activities & Programmes

One of the largest recent campaigns was the women in RA exhibition in the ministry of health with a special exhibition in one of the busiest malls in Budapest (2008).

The most important topics for the organisation in the coming years are:

- Work and reintegration in the workforce
- Patient education
- Raising awareness about RMDs
- Expanding the volunteers network
- Access to the latest therapies

Skills the organisation would like to learn:

- Raising public awareness campaigns
- Programmes for elderly people

Youth activities

Contact: Eszter Rozan
Email: eszterrozan@gmail.com
Tel/Skype: +36 30 689 94 51

Youth Organisation & Structure

Currently there is no separate youth group. Responsible for youth activities and related question is Eszter Rozan.
Gigtarfélag Íslands
Icelandic League Against Rheumatism

Address of the organisation

Street: Ármúli 5
City/Town: Reykjavik
ZIP/Postal Code: IS – 108
Country: Iceland
Tel: 0035 453 036 00
Email: gigt@gigt.is
Website: www.gigt.is

Name and title of President, Treasurer and General Manager/Secretary

President: Dóra Ingvadóttir
Treasurer: Guðrún Birna Jörgensen
General Manager/Secretary: Emil Thoroddson

Liaison person with EULAR

Name: Emil Thoroddson
Email: emilthor@gigt.is
Tel: 0035 453 036 00

About the organisation

Gigtarfélag Íslands was founded in 1976

The aims of the organisation are:
• Raise awareness about RMDs
• Improve the quality of life for people with RMDs
• Promote education for people with RMDs
• Provide information and support to people with RMDs.

All types of RMDs are represented by the organisation including fibromyalgia and osteoporosis.

The head office is in the capital Reykjavik, run by staff members and volunteers. The organisation has regional branches all over the country, driven by volunteers, with backup and support from the head office. Members are 5,030.
**Gigtarfélag Íslands**
Icelandic League Against Rheumatism

**Activities & Programmes**

**Skills the organisation could teach:**
How to run association in a big country, with few inhabitants. (pros and cons)

**Skills the organisation would like to improve:**
- New trends in self-management
- Youth activities
- How to use the social media in fundraising
- To keep volunteers, (reward, increase the value of their work)

**Youth activities**

- Age groups represented: **18-35 years old**
- Contact: Sunna Brá Stefánsdóttir
- Email: sunnabra@gigt.is
- Tel/Skype: 0035 453 036 00
- Website: www.gigt.is
- Facebook: www.facebook.com/groups/

**Youth Organisation & Structure**

There is an independent youth organisation comprising 10–50 members for 18-35 year olds.

**Youth Activities & Programmes**

Formal and informal meetings, Facebook activities.
Arthritis Ireland

Address of the organisation
Street: 1 Clanwilliam Square, Grand Canal Quay
City/Town: Dublin 2
Country: Ireland
Tel: +353 (0) 166 181 88
Email: info@arthritisireland.ie
Website: www.arthritisireland.ie

Name and title of President, Treasurer and General Manager/Secretary
President: John O’Flynn
Treasurer: Michael Kelly
General Manager/Secretary: John Church

Liaison person with EULAR
Name: John Church
Email: jchurch@arthritisireland.ie
Tel: +353 (0) 164 702 05

Youth activities
Age groups represented: 0–45
Contact: Laura Hickey
Email: lhickey@arthritisireland.ie
Tel/Skype: 00353 1 661 8188
Website: www.arthritisireland.ie,
www.juvenilearthritis.ie
Facebook/Twitter: https://www.facebook.com/ArthritisIreland.ie,
https://www.facebook.com/juvenilearthritisireland,
https://www.facebook.com/YoungArthritisNetwork,
@arthritisie, @arthritisieyan

About the organisation
At Arthritis Ireland, our vision is of a future free from arthritis. Until that is achieved, we are here to help people take control of their disease while we invest in research to find new treatments and, ultimately, a cure.

We do this by:
• providing people with arthritis with self-management tools and supports to ease the physical pain and social isolation caused by arthritis; and
• using ongoing research to increase our understanding of the causes of the disease as we work towards finding a cure

Our ambition
• To reach out to every person living with and affected by arthritis in Ireland
• To create a population who are actively taking control of their disease and inspiring others living with chronic diseases
• To ensure the medical community see Arthritis Ireland as an integral part of treatment prescription
• To find new treatments and, ultimately, a cure

Arthritis Ireland is governed by a board of directors who give their time freely and generously to further the cause. Our board meets on a regular basis and has a number of sub-committees that progress the work outside of the fully engaging in a supportive role with the staff of Arthritis Ireland. We currently have 11 staff that are committed to making a big difference in the lives of people with arthritis. Arthritis Ireland has a volunteer network of inspirational people with arthritis. The network includes 20 branches and 22 walking groups right across the country with a total of more than 400 dedicated volunteers.
Arthritis Ireland

Activities & Programmes

Our work towards a future free from arthritis can be broken down broadly into 6 different areas:

1. We are working on a cure together
   In the last six years, we have gathered a research fund of 2.5m to create two research centres which will support and enhance all rheumatology research efforts throughout the country and position Ireland at the forefront of rheumatology internationally.

2. We are taking control together
   We empower people to take control of their disease by understanding it and the effects it can have, and knowing about the treatments available. We call this ethos ‘self-management’ and it is at the foundation of every aspect of our education and support programmes.

3. We are supporting children with arthritis together
   There are more than 1,000 children living with Juvenile Arthritis (JA) in Ireland. Families want a normal childhood for their child and our JA programme has been specially tailored to help achieve that.

4. We are bringing a community together
   Our extensive volunteer network provides local access to our support services and education programmes. They are also the local voice of Arthritis Ireland, raising awareness in the media and among politicians of the issues affecting people with arthritis in their area.

5. We are creating better understanding together
   In 2013 we were in the media more than once a day throughout the whole year, spreading the message that arthritis is a serious chronic disease and a cause worth supporting.

6. We are fighting for better healthcare services together
   By influencing and working with the key decision and policy makers, we have been able to improve healthcare services for people with arthritis and create a better working environment.

Youth Organisation & Structure

Arthritis Ireland has a full time Juvenile Arthritis programme which is run by our Youth & Family Officer. This programme also includes a number of dedicated volunteers who take part in our events and support children and teenagers living with JA.

Arthritis Ireland has an active network for the 18–50 youth group with a dedicated group called the “Young Arthritis Network”. This group is made up of a voluntary committee and is supported by Arthritis Ireland’s Youth & Family Officer.

Youth Activities & Programmes

Arthritis Ireland has a full time Juvenile Arthritis programme providing a range of different services including:

- A dedicated JA Helpline
- Constant presence in the Children’s pediatric hospital
- JA Family Days
- JA teen week “The JA Road Trip”
- JA Information service online and in print. (www.juvenilearthritis.ie)
- Parent2Parent Network providing peer to peer support for parents

In addition to our services, Arthritis Ireland also advocates for better healthcare services for families living with JA.

We offer a range of different services for the youth programme:

- Self-Management Programmes for younger people living with arthritis
- A online private support groups for under 50’s including pregnancy and parenting.
- Walking & hillwalking groups
- Social events / gatherings
- Social media via twitter and facebook
INBAR –
Israeli Arthritis Foundation
& Lupus Org

Address of the organisation

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Street</td>
<td>16 Hanaziv St</td>
</tr>
<tr>
<td>City/Town</td>
<td>Tel Aviv</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>6701806</td>
</tr>
<tr>
<td>Country</td>
<td>Israel</td>
</tr>
<tr>
<td>Tel</td>
<td>0097 235 613 832</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:inbar-il@015.net.il">inbar-il@015.net.il</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.inbar.org.il">www.inbar.org.il</a></td>
</tr>
</tbody>
</table>

About the organisation

INBAR Foundation was founded in 1985

In 2014 we represent the Lupus patients too.

The aims of the organisation are:

- Support patients with rheumatic and musculoskeletal diseases (RMDs)
- Raise awareness about RMDs
- Provide information about latest technologies and therapies

All types of RMDs are represented by the organisation. The organisation has only a head office run by two part-time paid staff members and volunteers. The total number of members is about 4,000 individual members. 17% of the Israeli population are RA Patients.

Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
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<tbody>
<tr>
<td>President</td>
<td>Ram Blass</td>
</tr>
<tr>
<td>Treasurer</td>
<td>Hanan Gruber</td>
</tr>
<tr>
<td>Honorary President</td>
<td>Prof. Michael Yaron</td>
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</table>

Liaison person with EULAR

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<th>Field</th>
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<tbody>
<tr>
<td>Name</td>
<td>Ofra Balaban</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:amotat_c@netvision.net.il">amotat_c@netvision.net.il</a></td>
</tr>
<tr>
<td>Tel</td>
<td>0097 235 047 778</td>
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</table>
INBAR –
Israeli Arthritis Foundation & Lupus Org

Activities & Programmes
One of the largest recent campaigns was a conference for children with RMDs and their parents and a specially designed project for the use of everyday items by people with RMDs.

INBAR has:
- Hot-line for patients
- Support groups
- Organisation of conferences in order to raise awareness about RMDs
- Cooperation with other NGOs
- Part of the Israeli health coalition
- Publication of a magazine in 4 languages
- Cooperation with student for engineering to create products to assist patients

Youth activities
Age groups represented:
20–40 years old and Parents with children with RMDs

Contact: Michal Berman
Email: inbar-il@zahav.net.il
Tel/Skype: 0097 235613832
Website: http://www.inbar.org.il/

Youth Organisation & Structure
There is no separate organisation for young people with RMDs at the moment. All activities are taking place within INBAR.

Youth Activities & Programmes
- Organisation of congress for parents with children with RMDs
- Educational programme for teachers in schools on how to adjust the classroom for a child with RMD
- Support to parents to receive their rights form from the government
- Cooperation with the paediatricians
ANMAR –
Associazione Nazionale Malati Reumatici

Address of the organisation

Street: Istituto Elena Bettini - Via Nicola Zabagia, 19
City/Town: Roma
ZIP/Postal Code: 10153
Country: Italy
Tel: +39 (0) 334 804 2748
Email: info@anmar-italia.it
Website: www.anmar-italia.it

Name and title of President, Treasurer and General Manager/Secretary

President: Renato Giannelli
Treasurer: Stella Rosi
General Manager/Secretary: Maria Grazia Pisu
Vice Presidents: Teresa Perinetto and Silvia Tonolo; Pare Delegate Sara Severoni

Liaison person with EULAR

Name: Ugo Giuseppe Viora
Email: viora@anmar-italia.it / ugo_viora@virgilio.it
Tel: +39 3351372113

About the organisation

ANMAR was founded in 1985
The aims of the organisation are:
• Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
• Strengthen and consolidate relations with regional organisations, other associations and organisations that take care of patients’ rights inside and outside Italy
• Improve the quality of life for people with RMDs
• Lobby for issues related to RMDs
All types of RMDs are represented by the organisation.
It’s a non-profit organisation nationwide, regionally and locally; it’s an umbrella association with 17 regional organisations (with about 12,000 individual members). These are run by volunteers with RMDs.
ANMAR – Associazione Nazionale Malati Reumatici

Activities & Programmes

The most important topics for the organisation in the coming years are:

• Interfacing with the Italian political institutions (central and regionally) to issue measures about prevention, care and rehabilitation of people with RMDs in order to facilitate their integration on the operative contest of the social-economic life of the country (Fit for work)
• Raising awareness about RMDs
• Motivating new volunteers and expanding the volunteers network
• Fundraising

Youth activities

Age groups represented: All ages
Contact: Silvia Ostuzzi
Email: ostuzzi@anmar-italia.it
Tel/Skype: +39 329 028 5619
Website: www.anmar-italia.it
Facebook/Twitter: ANMAR ITALIA.IT

Youth Organisation & Structure

The youth group was born in the third quarter of 2014 and we are still working on the structure and on how to make the organisation more efficient.
Our aim is to have one liaison person in each Italian Region and to make them able to have at least 3 young members in their operating team.

Youth Activities & Programmes

First programme: to strengthen our network we sent a letter to each president of the regional associations in ANMAR network to invite them to help us in our development.
Second one: to apply successfully to the Knowledge Transfer Programme offered by EULAR PARE.
LKLSSB - Latvijas Kaulu, locītavu un saistaudu slimnieku biedrība
Latvian Association of Bone, Joint and Connective Tissue Diseases’ Patients

Address of the organisation

Street: Nicgales 21–49
City/Town: Riga
ZIP/Postal Code: LV – 1035
Country: Latvia
Tel: +371 (0) 298 241 55
Email: marika.karlsone@gmail.com
Website: www.reimatik.lv

Name and title of President, Treasurer and General Manager/Secretary

President: Janis Arajas
Treasurer: Rudite Priede
General Manager/Secretary: Marika Karlsone

Liaison person with EULAR

Name: Marika Karlsone
Email: marika.karlsone@gmail.com
Tel: +371 (0) 298 241 55

About the organisation

L.K.L.S.S.B was founded in 1998

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients
- Provide education for people with RMDs
- Establish groups of people who share the same interests

The types of RMDs that are represented by the organisation are the following: Rheumatoid arthritis, ankylosing spondylitis, juvenile arthritis, lupus (SLE) and vasculitis. The organisation has 5 regional branches which cover a part of the country and they are run by volunteers with RMDs. In total the organisation counts about 650 individual members.
LKLSSB - Latvijas Kaulu, locītavu un saistaudu slimnieku biedrība
Latvian Association of Bone, Joint and Connective Tissue Diseases’ Patients

Activities & Programmes

One of the largest recent campaigns was the conference People with RA - change your quality of life, do it by yourself.

The most important topics for the organisation in the coming years are:

- Renew youth group work by their own leadership
- Patient school regularity
- Lobbying for access to biologics treatment
- Renovating the organisation’s website
- Becoming more involved in social media
- Hiring a professional project manager

Youth activities

There is a youth organisation comprising up to 10 members for 18-30 year olds

Name: Mikelis Bendiks
Email: mikelis.bendiks@gmail.com
Lietuvos Artrito Asociacija
Lithuanian Arthritis Association

**Address of the organisation**

- **Street:** Zygimantu 9
- **City/Town:** Vilnius
- **ZIP/Postal Code:** LT-01102
- **Country:** Lithuania
- **Tel:** 0037 02312249
- **Email:** artritas.laa@gmail.com
- **Website:** www.arthritis.lt

**Name and title of President, Treasurer and General Manager/Secretary**

- **President:** Ona Stefanija Telyčienė
- **Treasurer:** Aldona Liutkuvienė
- **General Manager/Secretary:** Jolanta Dadoniene

**Liaison person with EULAR**

- **Name:** Jolanta Dadonienė
- **Email:** jolanta.dadoniene@ekmi.vu.lt
- **Tel:** +370 66222092

**About the organisation**

Lietuvos Artrito Asociacija was founded in 1998.

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs) in our country
- Campaigning patients’ rights in different levels of public health and politics
- Improve the quality of life for people with RMDs through organised activities

The organisation has 9 independent regional organisations which cover the whole country and they are run by 3 leading staff members and volunteers with RMDs. In total the organisation has approximately 2,000 individual members.

There are few organisations working in association with Lithuanian arthritis association, but are not the members of LAA, they are mostly self dependent organisations. Their activities are related to 1) children rheumatic diseases; 2) Ankylosing spondilitis (Bechterev disease) organisation and 3) patients with Lupus disease (registered in 2015). They include members of different ages and of different expectations from the organisations they participate.
**Lietuvos Artrito Asociacija**
Lithuanian Arthritis Association

### Activities & Programmes

**What the organisation could teach:**
- The organisation is skillful in providing knowledge
- How to organise and maintain the self management groups and how to educate and teach the instructors of such groups.
- Training on how to develop and publish a journal
- We have special knowledge in organizing rehabilitation groups for our members

**What the organisation would like to learn:**
- We would like to acquire or deepen our knowledge in recruiting young members to our organisation
- We still need skills in fundraising to support our activities

### Youth activities

No youth activities at present.
Malta-ARAM – Arthritis and Rheumatism Association Malta

Address of the organisation

- Street: P.O. Box 55
- City/Town: Birkirkara
- ZIP/Postal Code: MT – BKr 1000
- Country: Malta
- Tel: 0035 699 259 532
- Email: aramalta@gmail.com
- Website: www.aramalta.org

Name and title of President, Treasurer and General Manager/Secretary

- President: Mary Vella
- Treasurer: Josephine Camilleri
- General Manager/Secretary: Marie-Therese Camenzuli

Liaison person with EULAR

- Name: Mary Vella
- Email: maryvellamalta@gmail.com
- Tel: 00356 79233454

About the organisation

ARAM was founded in 2007.

The aims of the organisation are:

To provide a comprehensive information and understanding regarding all forms of rheumatic and musculoskeletal diseases (RMDs) and therefore to create education, awareness, understanding and acceptance of the said health conditions.

To promote and offer support to members including the creation of support groups, organizing educational seminars conducted by rheumatology professionals. Organising physical activities, self-management courses, and by any other means that can be of benefit to the patient.

To represent the national interest of the members by assisting them by advice and moral support and to represent them in matters concerning RMDs.

To urge authorities to give due considerations and help where needed to the association and its members.

To encourage further medical research and education in the field of the latest treatments regarding RMDs.

Work with the government to promote healthy living and self-management courses.

- Campaign for equal rights and treatment for people with RMDs both local and International
- To establish a young active group.

The types of RMDs that are represented by the organisation are: rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile arthritis, fibromyalgia, scleroderma and osteoporosis. The organisation has only a central administration which is run by volunteers with RMDs. In total the organisation counts about 380 individual members.
### Malta-ARAM – Arthritis and Rheumatism Association Malta

#### Activities & Programmes

- Monthly educational seminars.
- Physical activities to improve well being.
- Self-management Courses.
- Activities to generate funds to promote and aid the association in fulfilling its objectives.
- Conference for the GPs on early referral.
- Training for committee members organised by the Malta Voluntary Council for NGOs.
- Monthly committee meetings.
- Celebration of WAD.

#### Youth activities

- **Age groups represented:** 16-35 years old
- **Contact:** Silvan Cortis
- **Email:** sylvan.cortis@gmail.com
- **Tel/Skype:** 0035 699 430 710
- **Website:** www.aramalta.org

#### Youth Organisation & Structure

- In the process of establishing a youth group

#### Youth Activities & Programmes

- Organised one brain storming session conducted by a Rheumatologist Consultant on Youths.
- A seminar is planned.
**Association for Helping Persons with Rheumatic Diseases**
Rheumatism Association Montenegro

**Address of the organisation**
- **Street:** Bulevar Svetog Petra Cetinjskog 65
- **City/Town:** Podgorica
- **ZIP/Postal Code:** MO – 81000
- **Country:** Montenegro
- **Tel:** 0038 269 506 022
- **Email:** senas@t-com.me

**Name and title of President, Treasurer and General Manager/Secretary**
- **President:** Senka Stijepovic
- **Treasurer:** Lidija Brajovic
- **General Manager/Secretary:** Igor Medojevic

**Liaison person with EULAR**
- **Name:** Senka Stijepovic
- **Email:** senas@t-com.me
- **Tel:** 0038 269 506 022

**About the organisation**

**Association for Helping Persons with Rheumatic Diseases was founded in 2003**

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients

The types of RMDs that are represented by the organisation are the following: Rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, juvenile arthritis, osteoporosis, fibromyalgia, lupus (SLE), scleroderma, vasculitis, Sjogren, myositis, and myalgia. The organisation has a central administration, run by volunteers with RMDs. In total the organisation counts about 2,150 individual members.
**Association for Helping Persons with Rheumatic Diseases**
Rheumatism Association Montenegro

<table>
<thead>
<tr>
<th>Activities &amp; Programmes</th>
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</thead>
<tbody>
<tr>
<td>One of the largest recent campaigns was the <em>Let’s work together</em> campaign (introducing patients to disability rights laws and discovering new opportunities for people with RMDs in the workplace).</td>
</tr>
<tr>
<td>The most important topics for the organisation in the coming years are:</td>
</tr>
<tr>
<td>• Better access to education and work</td>
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<tr>
<td>• Access to rehabilitation and the latest therapies</td>
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<td>• Implementing EULAR Charter for Work</td>
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<table>
<thead>
<tr>
<th>Youth activities</th>
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<tbody>
<tr>
<td>No youth activities at present.</td>
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National Association ReumaZorg Nederland

Address of the organisation

<table>
<thead>
<tr>
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<th>PO Box 58</th>
</tr>
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<tbody>
<tr>
<td>City/Town</td>
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</tr>
<tr>
<td>ZIP/Postal Code</td>
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</tr>
<tr>
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<td>The Netherlands</td>
</tr>
<tr>
<td>Tel</td>
<td>(+) 31 6 18647139</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:info@reumazorgnederland.nl">info@reumazorgnederland.nl</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.reumazorgnederland.nl">www.reumazorgnederland.nl</a></td>
</tr>
<tr>
<td>Facebook</td>
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</tr>
<tr>
<td>Twitter</td>
<td>@ReumaZorgNL</td>
</tr>
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Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President</th>
<th>G. Willemsen-de Mey M.A.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer</td>
<td>L. Platenkamp, accountant</td>
</tr>
<tr>
<td>Secretary</td>
<td>J. Vooijs</td>
</tr>
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</table>

Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name</th>
<th>Gerardine Willemsen-de Mey M.A.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:voorzitter@reumazorgnederland.nl">voorzitter@reumazorgnederland.nl</a></td>
</tr>
<tr>
<td>Tel</td>
<td>(+) 31 6 18647139</td>
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</tbody>
</table>

About the organisation

The National Association ReumaZorg Nederland (RZN) was founded in 2014

The National Association ReumaZorg Nederland (RZN) is a Dutch umbrella body and consists of individual patients with RMDs and patient organisations as members. RZN has as its overall aim to improve the situation of all people with rheumatic and musculoskeletal diseases (RMDs), help shape policy and contribute to health service.

The organisation wants to achieve this goal by:

- Raising awareness about rheumatic and musculoskeletal diseases (RMDs)
- Supporting member organisations in organizing self-management activities and services for people with rheumatic and musculoskeletal diseases (RMDs)
- Stimulating and supporting participation of patients in research
- Campaigning for the improvement of medical treatment, work, psychological and social support
- Promote contacts with fellow patients.
- Work together with other national and international (patient) organisations on shaping policy.

All types of RMDs, musculoskeletal, inflammatory or degenerative, are represented by the organisation. The organisation works together with regional and local patient-led and patient-based organisations covering the country and run by volunteers with RMDs and with disease-specific organisations, for example on participating in PARE activities.
National Association
ReumaZorg Nederland

Activities & Programmes
The most important topics for the organisation in the coming year(s) are:
• Raising awareness about RMDs and the impact of the condition(s) on people’s lives and on society
• Providing and advocating patient education and training.
• Increasing the number of younger members in the organisation and in member organisations
• Promote work and re-integration in the workforce of people with RMD’s.
• Work together with other national and international (patient) organisations on different issues concerning organisational tasks and the care for people with RMD’s.

Youth Organisation & Structure
Age groups represented: 16 - 30 years old.
The National Association ReumaZorg Nederland (RZN) offers support, information, workshops on different themes, events and gatherings to young people with RMDs.

Contact: A. van Woudenberg
Email: communicatie@reumazorgnederland.nl
Website: www.reumazorgnederland.nl
Facebook: www.facebook.com/reumazorgnederland
Twitter: @ReumaZorgNL

Youth activities
• A group of young people within the National Association ReumaZorg Nederland (RZN) is busy with organising events and gatherings with the aim of empowering young people with RMDs.
Website: www.reumazorgnederland.nl
Facebook: www.facebook.com/reumazorgnederland
Twitter: @ReumaZorgNL

• Youth-R-Well.com is a separate Dutch youth organisation, offering support and information, social gatherings, website and courses to young people with rheumatic and musculoskeletal diseases (RMDs) between the ages of 16 to 30 years. The contact with the young people is mainly through social media and their website.
Website: www.youth-r-well.com
Facebook/Twitter: @YouthRWell
### Norwegian Rheumatism Association

**Address of the organisation**

<table>
<thead>
<tr>
<th>Street:</th>
<th>prof. dahlsgt. 32</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town:</td>
<td>Oslo</td>
</tr>
<tr>
<td>ZIP/Postal Code:</td>
<td>0203</td>
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<tr>
<td>Country:</td>
<td>Norway</td>
</tr>
<tr>
<td>Tel:</td>
<td>0047 22547600</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:post@revmatiker.no">post@revmatiker.no</a></td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.revmatiker.no">www.revmatiker.no</a></td>
</tr>
</tbody>
</table>

**Name and title of President, Treasurer and General Manager/Secretary**

| President: | Jan Grundt |
| Treasurer: |           |
| General Manager/Secretary: | Tone Granaas |

**Liaison person with EULAR**

| Name: | Tone Granaas |
| Email: | tg@revmatiker.no |
| Tel: | 0047 45664746 |

### About the organisation

**Norsk Revmatikerforbund (NRF) was founded in 1951**

The aims of the organisation are:

- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients

All types of RMDs are represented by the organisation. The organisation consists of 225 local groups with local branches in all of our 19 counties. Within the branches there are individual diagnostic groups and children and youth in all counties.

At the national level and in the counties we are a total of 30 paid employees.

In addition, in all counties and local groups there are volunteers. The total number of individual members is about 34,000 people.
Norwegian Rheumatism Association

Activities & Programmes

In recent years we have worked with economic perspective on health and work. In this work we organised several different campaigns, conferences and political lobbying.

The most important topic for the organisation in the coming years is:
• Strengthen the organisation - increase growth in membership and still have a high focus on the rehabilitation field.

Youth activities

The ages of **0 - 35 years**

Contact: Joachim Sagen
Email: js@revmatiker.no
Website: http://www.burg.no
Tel/Skype: 0047 95756723
Facebook/Twitter: facebook.com/burgnorge

Youth Organisation & Structure

BURG secretariat consisting of two persons.
The board has five members local Burg groups - volunteers throughout Norway

Youth Activities & Programmes

Educational and social courses/gatherings for different age groups (e.g. 13-17 and 18-35) as well as for their families, e.g. seminars for parents
Polish Rheuma Federation “REF”
Ogólnopolska Federacja Stowarzyszen Reumatykow “REF”

Address of the organisation

<table>
<thead>
<tr>
<th>Street:</th>
<th>Spartanska 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town:</td>
<td>Warsaw</td>
</tr>
<tr>
<td>ZIP/Postal Code:</td>
<td>02-637</td>
</tr>
<tr>
<td>Country:</td>
<td>Poland</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:REF@biznespoczta.pl">REF@biznespoczta.pl</a></td>
</tr>
<tr>
<td>Website:</td>
<td>ref.mixxt.pl</td>
</tr>
</tbody>
</table>

Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President:</th>
<th>Jolanta Grygielska</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer:</td>
<td>Barbara Waclawek</td>
</tr>
<tr>
<td>General Manager/</td>
<td></td>
</tr>
<tr>
<td>Secretary:</td>
<td>Brygida Widera</td>
</tr>
</tbody>
</table>

Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name:</th>
<th>Bozena Moskaliewicz/</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jolanta Grygielska</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:bozena.moskaliewicz@gmail.com">bozena.moskaliewicz@gmail.com</a>/</td>
</tr>
<tr>
<td></td>
<td><a href="mailto:jgrygielska@wp.pl">jgrygielska@wp.pl</a></td>
</tr>
<tr>
<td>Tel:</td>
<td>+48502222843/</td>
</tr>
<tr>
<td></td>
<td>+48606883425</td>
</tr>
</tbody>
</table>

About the organisation

Polish Rheuma Federation „REF” was founded in 2000

It is an umbrella organisation of associations of rheumatic people. The aims of the organisation are:

1) Representing the interests of people with rheumatic and musculoskeletal diseases (RMDs), with particular attention to people with disabilities
2) The defense and advocacy of their rights
3) Obtaining the status of reviser of legal regulations affecting the interests of people with rheumatic disease
4) Exercise social control and regulation pressure group against the power structures of state and local government for the benefit of those people
Polish Rheuma Federation “REF”
Ogólnopolska Federacja Stowarzyszenia Reumatyków “REF”

Activities & Programmes

1) Participation in social consultations of legal regulations connected with health and disability
2) Participation in meetings with Minister of Health
3) Organisation of session for representatives of associations of rheumatic people during National Meetings of Rheumatology and Congress of Polish Society of Rheumatology
4) Co-ordination of national and European events as World Arthritis Day

Youth activities

Age groups represented: 0–30 years old
Contact: Monika Zientek
Email: m.zientek@3majmysierazem.pl
Website: www.3majmysierazem.pl

Youth Organisation & Structure

There is an independent youth organisation comprising 10–50 members for up to 30 years old, offering: Website Twitter, Facebook, yearly national conferences with workshops.
LPCDR – Liga Portuguesa Contra as Doenças Reumáticas
Portuguese League Against Rheumatic Diseases

Address of the organisation

<table>
<thead>
<tr>
<th>Street</th>
<th>Rua Quinta do Loureiro, 13 Loja 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town</td>
<td>Lisbon</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>1350-410</td>
</tr>
<tr>
<td>Country</td>
<td>Portugal</td>
</tr>
<tr>
<td>Tel</td>
<td>0035 121 364 877 6</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:lpcdr@lpcdr.org.pt">lpcdr@lpcdr.org.pt</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.lpcdr.org.pt">www.lpcdr.org.pt</a></td>
</tr>
</tbody>
</table>

Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President</th>
<th>Elsa Mateus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer</td>
<td>Cristina Carvalho</td>
</tr>
<tr>
<td>General Manager/Secretary</td>
<td>Mireille Amaral</td>
</tr>
<tr>
<td>Vice-Chairperson</td>
<td>Prof. Helena Canhão</td>
</tr>
</tbody>
</table>

Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name</th>
<th>Elsa Frazão Mateus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:elsafrazamateus@gmail.com">elsafrazamateus@gmail.com</a></td>
</tr>
<tr>
<td>Tel</td>
<td>0035 191 677 914 5</td>
</tr>
</tbody>
</table>

About the organisation

Liga Portuguesa Contra as Doenças Reumáticas was founded in 1982

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients and fellow organisations
- Support and educate RMD patients.

The organisation represents all types of RMDs, according to usual distribution and prevalence on general population.

The organisation has no local branches. It is run by a Board of Directors (volunteers with RMDs and rheumatologists), other volunteers engaged in specific Patient Groups and/or Patient Support Group, and by one member of paid staff (Administrative Assistant Ana Ribeiro). In total the number of individual members is approximately 500.

The most important topics for the organisation in the coming years are:
- Fundraising
- Extending the network of volunteers
- Acquiring expertise in certain areas.

Two of our members were trained as Patient Research Partners (RA & SS) and are members of EULAR PRP network.
LPCDR – Liga Portuguesa Contra as Doenças Reumáticas
Portuguese League Against Rheumatic Diseases

Activities & Programmes

- Newsletter’s publication (every three month)
- Website and Facebook page maintenance
- Contacts with national and european associations as well as with the “Plataforma Saúde em Diálogo” (patients and consumers organisations) and the Portuguese Society of Rheumatology
- Awareness and support activities of our three Patients Groups: Osteoarthritis, Chronic Pain and Sjögren Syndrome
- Annual Meeting for patients (LPCDR’s Forum)
- Participation in several events related with Health and/or Rheumatic Diseases
- Organisation on a national level of the Edgar Stene Prize
- Organisation on a national level of the photo contest “Chronicles of Pain”
- Volunteer Group: Patient’s support; organisation of social events (cultural events, physical activity promotion, etc)
- Participation in European meetings: EULAR Congress and EULAR Conference for PARE
- Partnerships & Protocols

Youth activities

Contact: Elsa Frazão Mateus
Email: elsafranzaomateus@gmail.com
Tel/Skype: + 00 351 916779145

Youth Organisation & Structure

No youth group or organisation at the moment. However, there is a specific association in Portugal, which is associated of the LPCDR (ANDAI – National Association of Patients with Arthritis and other Childhood Rheumatisms).

http://www.andai.org.pt
https://pt-pt.facebook.com/pages/Associa%C3%A7%C3%A3o-Nacional-de-Doentes-com-Artrite-Infantil/25720504315228
## Liga Romana Contra Reumatismului

### Address of the organisation

<table>
<thead>
<tr>
<th>Street:</th>
<th>Strada Thomas Masaryk Nr. 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town:</td>
<td>Bucharest</td>
</tr>
<tr>
<td>ZIP/Postal Code:</td>
<td>Ro – 70231</td>
</tr>
<tr>
<td>Country:</td>
<td>Romania</td>
</tr>
<tr>
<td>Tel:</td>
<td>0040 212 116 848</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:liga.reumatism@gmail.com">liga.reumatism@gmail.com</a></td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.reumatism.ro">www.reumatism.ro</a></td>
</tr>
</tbody>
</table>

### About the organisation

**Liga romana contra reumatismului was founded in 2002**

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights & treatment
- Improve the quality of life for people with RMDs
- Ensure permanent, easy access to accurate high quality information & practical guidelines on how to cope with the disease in everyday life
- Promote contacts with fellow patients

All types of RMDs are represented. The organisation has no local branches & is run by volunteers with RMDs. It counts about 650 member patients & 40 doctors & HPs.

### Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President:</th>
<th>Catalin Codreanu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer:</td>
<td>Ileana Galea</td>
</tr>
<tr>
<td>General Manager/</td>
<td>Marieta Stoicescu</td>
</tr>
<tr>
<td>Secretary:</td>
<td></td>
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### Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name:</th>
<th>Codruta Zabalan</th>
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<tbody>
<tr>
<td>Email:</td>
<td><a href="mailto:codruta.filip@gmail.com">codruta.filip@gmail.com</a></td>
</tr>
<tr>
<td>Tel:</td>
<td>0040 721 240 545</td>
</tr>
</tbody>
</table>
Liga Romana Contra Reumatismului

Activities & Programmes

One of the largest recent campaigns was the Inspir Art project, an experiential series of art workshops encouraging RA patients, rheumatologists & artists to work in partnership, sharing views, articulating personal perspectives. 12 paintings have been displayed in several (inter-)national exhibitions (www.articulatera.com). This project was about identifying appropriate ways of addressing RA, both medically & emotionally, to improve the quality of life for patients.

The most important topics for the organisation in the coming years are:

- Providing education for people with RMDs
- Raising awareness about RMDs
- Encouraging industry involvement in developing media campaigns & joint messages
- Campaigning for early diagnosis
- Gaining new active members & volunteers
- Establishing local branches all over the country

Skills the organisation would like to improve:

- fundraising;
- self-management (courses, trainers);
- gaining new active members and volunteers;
- running successful awareness campaigns;
- working in partnership;
- developing programmes for specific groups
- media training

Youth activities

Contact: Florin Catrina
Email: fmcatrina@gmail.com
Tel/Skype: 0040 758 117 040

Youth Organisation & Structure

A private Facebook group (18-35) has been created on Facebook
## N.A.D.E.G.D.A. - National Public Organisation of disabled people
Russian League Against Rheumatism

### Address of the organisation

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Street</td>
<td>fl. 99, st. Akademika Vargy 22</td>
</tr>
<tr>
<td>City/Town</td>
<td>Moscow</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>RU – 177133</td>
</tr>
<tr>
<td>Country</td>
<td>Russian Federation</td>
</tr>
<tr>
<td>Tel</td>
<td>0084 953 384 625</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:buna17@mail.ru">buna17@mail.ru</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.revmo-nadegda.ru">www.revmo-nadegda.ru</a></td>
</tr>
</tbody>
</table>

### Name and title of President, Treasurer and General Manager/Secretary

- **President:** Natalia Bulgakova
- **Treasurer:** Larisa Kameneva
- **General Manager/Secretary:** Igor Golov

### Liaison person with EULAR

- **Name:** Natalia Bulgakova
- **Email:** buna17@mail.ru
- **Tel:** 0084 953 384 625

### About the organisation

**N.A.D.E.G.D.A was founded in 2006**

The aims of the organisation are:
- Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Promote contacts with fellow patients

All types of RMDs are represented by the organisation. The organisation has 47 regional branches, run by volunteers with RMDs, covering the whole country.
N.A.D.E.G.D.A. - National Public Organisation of disabled people
Russian League Against Rheumatism

Activities & Programmes

The most important topics for the organisation in the coming years are:
- Easy (free) access to medicines
- Creating outpatients specialised rheumatology centres
- Fundraising
- Establishing offices for all regional branches
- Educating volunteers in leading regional groups

Youth activities

No youth activities at present.
ORS – The Association of Rheumatic Diseases Patients of the Republic of Serbia
Serbian League Against Rheumatism

Address of the organisation
Street: Resavska 69
City/Town: Belgrade
ZIP/Postal Code: 11000
Country: Serbia
Tel: 00381 113 612 376
Email: mlapcevic@ors.rs
Website: www.ors.rs

Name and title of President, Treasurer and General Manager/Secretary
President: Mirjana Lapcevic
Treasurer: Zora Radovic
General Manager/Secretary: Zora Radovic

Liaison person with EULAR
Name: Marija Kosanovic
Email: mkosanovic@ors.rs
Tel: 00381 642 802 059

About the organisation
ORS was founded in 2007
The aims of the organisation are:
• Raise awareness about rheumatic and musculoskeletal diseases (RMDs)
• Support people with RMDs by providing education and rehabilitation services in order to improve the quality of their lives

All RMDs are represented by our organisation. The organisation has 5 local branches and 2 sub-branches, run by volunteers with RMDs, covering the whole country. The organisation counts about 1,400 individual members.
## ORS – The Association of Rheumatic Diseases Patients of the Republic of Serbia

**Serbian League Against Rheumatism**

### Activities & Programmes

The most important activities are:

- Providing educational meetings for people with RMDs
- Organising psycho-social support for our members
- Lobbying the government on behalf of people with RMDs
- Campaigning for prevention and early diagnosis
- Competing for the projects which can improve quality of life of people with RMDs
- Organising and coordinating the Annual Congress of Rheumatologists together with the members of our association. During the Congress there are two programmes organised for both rheumatologists and patients

### Youth Organisation & Structure

In Serbia there is a separate organisation under the name of Serbian Society of Parents and Children with Rheumatic Diseases.

It was founded in 2003 and its aims and tasks were and still are:

- To provide information on symptoms, available treatments, rehabilitation options and re-socialisation to parents of children suffering from RMDs
- To educate its members, and, through this education process, to better inform and improve the quality of life for children suffering from rheumatic diseases
- To lobby the government
- To liaise and cooperate with other similar organisations

### Youth activities

<table>
<thead>
<tr>
<th>Age groups represented: <strong>0–18 years old</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Contact:</strong> Dimitrije Stojanovic</td>
</tr>
<tr>
<td><strong>Email:</strong> <a href="mailto:dimitrije_998@hotmail.com">dimitrije_998@hotmail.com</a></td>
</tr>
<tr>
<td><strong>Tel/Skype:</strong> 00 381 65 2033328</td>
</tr>
<tr>
<td><strong>Website:</strong> <a href="http://www.nasedete.com">http://www.nasedete.com</a></td>
</tr>
<tr>
<td><strong>Facebook/Twitter:</strong> Udruženje roditelja i dece obolele od reumatskih bolesti</td>
</tr>
</tbody>
</table>

### Youth Activities & Programmes

The most important topics for the organisation are:

- Organising educational meetings for the parents and children with RMDs
- Campaigning for raising awareness for help and support of children and young people suffering from RMDs
- Re-integration in the pre-school and schooling systems after diagnosing and rehabilitation
**Liga proti reumatizmu**  
Slovak League Against Rheumatism

### Address of the organisation

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td>Street</td>
<td>Nábrezie I. Krasku 4</td>
</tr>
<tr>
<td>City/Town</td>
<td>Piestany</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>92101</td>
</tr>
<tr>
<td>Country</td>
<td>Slovakia</td>
</tr>
<tr>
<td>Tel</td>
<td>+421 (0) 917 790 264</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:liga@mojareuma.sk">liga@mojareuma.sk</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.mojareuma.sk">www.mojareuma.sk</a></td>
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### Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>Role</th>
<th>Name and Title</th>
</tr>
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<tbody>
<tr>
<td>President</td>
<td>Mgr. Jana Dobšovicová Cernáková</td>
</tr>
<tr>
<td>Treasurer</td>
<td>Ing. Anna Jursíková</td>
</tr>
<tr>
<td>General Manager/Secretary</td>
<td>Bc. Zuzana Bendíková</td>
</tr>
</tbody>
</table>

### Liaison person with EULAR

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Petra Bednárová</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:petrabadnarova5@gmail.com">petrabadnarova5@gmail.com</a></td>
</tr>
<tr>
<td>Tel</td>
<td>+421 918 899 654</td>
</tr>
</tbody>
</table>

### About the organisation

Slovak League Against Rheumatism is a civic association with history of 25 years that educates, joins, organises, helps, provides support, advice and information, and connects its members.

The organisation covers 14 local branches in bigger Slovak towns and also two clubs: Club Kibik (“Little joint” – club for children) and The Butterfly Club (for patients with SLE).
**Liga proti reumatizmu**  
Slovak League  
Against Rheumatism

### Activities & Programmes
Looking for volunteers, working with them and keeping in touch. Also for more target-oriented marketing activities.

### Youth Organisation & Structure
Klub Klbič is managed by a Board composed of 5 members, 2 substitutes and 3 members of an Inspection Committee. The Board prepares activities and programmes for its members – young rheumatics in Slovakia.

The members of the Board and the Committee are elected for three years, with a possibility for re-election. The Board is governed by the SLAR bylaws, approved plan of action and budget (strategic and operational rules and guidelines).

### Youth activities
- **Age groups represented:** 0–35
- **Contact:** Petra Bednárová  
  Email: petrabednarova5@gmail.com  
  Tel/Skype: petkapetka55  
  Website: www.mojareuma.sk  
  Facebook/Twitter: https://www.facebook.com/groups/114342595303241/?fref=ts
# Slovenian Rheumatism Association (DRS)

## Address of the organisation

<table>
<thead>
<tr>
<th>Street</th>
<th>Parmova 53</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town</td>
<td>Ljubljana</td>
</tr>
<tr>
<td>ZIP/Postal Code</td>
<td>SI -1000</td>
</tr>
<tr>
<td>Country</td>
<td>SLOVENIA</td>
</tr>
<tr>
<td>Tel</td>
<td>0038 659 075 360</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:drustvo@revmatiki.si">drustvo@revmatiki.si</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.revmatiki.si">www.revmatiki.si</a></td>
</tr>
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</table>

## Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President</th>
<th>Andrej Gregorčič</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treasurer</td>
<td>Angela Cerar</td>
</tr>
<tr>
<td>General Manager/Secretary</td>
<td>Petra Zajc</td>
</tr>
<tr>
<td>Programmes coordinator</td>
<td>Maja Dimnik</td>
</tr>
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## Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name</th>
<th>Petra Zajc</th>
</tr>
</thead>
<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:petra@gmail.com">petra@gmail.com</a></td>
</tr>
<tr>
<td>Tel</td>
<td>+38 641 575 103</td>
</tr>
</tbody>
</table>

## About the organisation

**DRS was founded 1983**

We represent patients with all types of inflammatory rheumatic diseases (RA, SpA, AS, JIA, SLE, etc.). Our organisation has 13 branches which cover all areas of the country and it is run by volunteers with rheumatic and musculoskeletal diseases (RMDs) and two paid staff. The current number of members is about 1,550 individuals. In Slovenia, inflammatory rheumatic diseases affect around 50,000 people.

Our mission: We are a user led organisation with a mission to find solutions for social and health problems for people with RMDs.

Our aim is to achieve better quality of life and health care for everyone who is affected by this chronic, progressive disease. We strive to empower patients and also advocate their rights in dialogue with political and other stakeholders.

The aims are also:

- Raise awareness about (RMDs)
- Campaign for equal rights and treatment
- Improve the quality of life for people with RMDs
- Access to healthcare and newest medicines
- Education for people with RMD's
- Promote contacts with fellow patients

One of the priorities of our organisation is to reduce the burden of RMDs on the individual and society and to improve the process of early diagnosis, treatment, prevention and rehabilitation of inflammatory rheumatic diseases.
Slovenian Rheumatism Association (DRS)

Activities & Programmes

To achieve our mission we perform eight social programmes throughout the year:

1. Rehabilitation programme and maintaining mental and physical health
2. Educational and training programme for adult patients and their families (to provide relevant information and to empower patients)
3. Educational and training programme for children and adolescents with juvenile idiopathic arthritis (JIA) and their families
4. Counseling programme for independent living for people with disabilities
5. Personal assistance, care and physical help for elderly patients and patients with disabilities
6. Informational activities (booklets, brochures, web pages, awareness campaigns, communication with the media etc.)
7. Sports and recreational activities
8. Cultural activities

Other activities:
Identification of the interests of persons with inflammatory rheumatism and advocacy of their needs and rights in dialogue with the relevant institutions and policy makers. We also carry out all other activities that contribute to reducing discrimination and improving living conditions, promote human rights, and we strive to achieve active participation and independent living of sufferers and people with disabilities.

Recent actions:
One of the largest recent campaigns was in 2014, in light of the mission of our association to improve the treatment of patients with inflammatory rheumatic diseases, in June 2014 we launched a raising awareness campaign among patients, general public and general practitioners about spondyloarthritis (SpA). Approximately 1.9 percent of the Slovenian population is affected by SpA.

The main objectives of the campaign were:
- To provide relevant information on SpA and on the basis of those information encourage people who recognize signs of inflammatory back pain, to visit your GPs, who then referrals them to a rheumatologist
- Increase awareness among GPs about SpA and educate them on how to recognise the first symptoms
- Accelerate the process of early referral of potential patients from GPs to the rheumatologist.

Quick referral to a rheumatologist is essential for optimal treatment of patients with SpA (early and appropriate treatment)

Youth activities

No youth activities at the moment.
Liga Reumatológica Española (LIRE)
Spanish League Against Rheumatism

Address of the organisation

Street: Bajo Left B 2, Hilarión Eslava Street
City/Town: Madrid
ZIP/Postal Code: 28015
Country: Spain
Tel: 00 34 911 250 150/00 34 692 271 099
Email: lire@lire.es
Website: www.lire.es

Name and title of President, Treasurer and General Manager/Secretary

President: Benito Martos Borrega
Treasurer: Santos Yuste Zazo
General Manager/Secretary: Juan José Díaz

Liaison person with EULAR

Name: Gonzalo Aldeanueva
Email: gonzalde@gmail.com
Tel: +34 (0) 91 125 01 50

About the organisation

LIRE, since its incorporation as a non-profit association in 1973, is conducting a major task for raising awareness about rheumatic and musculoskeletal diseases (RMDs).

Its particular purpose is to promote and develop the fight against RMDs and their consequences both at individual and social level. LIRE develops and promotes educational activities aimed at prevention and prophylaxis of RMDs, treatment and rehabilitation as well as assistance and relief for those affected by these diseases, in accordance with statutory and regulatory provisions relating to the subject.
Liga Reumatológica Española (LIRE)
Spanish League Against Rheumatism

Activities & Programmes

- Facilitating the creation and consolidation of new associations
- Holding informative seminars and conferences for people with RMDs and doctors
- Running national projects and specific programmes for groups at risk of social exclusion

The most important topics for the organisation in the coming years are:

- More financial support from pharmaceutical companies and state institutions to develop their work with patients’ associations
- Enabling people with RMDs with opportunities for greater participation and collaboration at national and international level
- Organising scientific conferences and congresses for people with RMDs.

Youth activities

No youth activities at the moment.
# Reumatikerförbundet
Swedish Rheumatism Association

## Address of the organisation
<table>
<thead>
<tr>
<th>Street:</th>
<th>P.O.Box 12851</th>
</tr>
</thead>
<tbody>
<tr>
<td>City/Town:</td>
<td>Stockholm</td>
</tr>
<tr>
<td>ZIP/Postal Code:</td>
<td>SE – 11298</td>
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<tr>
<td>Country:</td>
<td>Sweden</td>
</tr>
<tr>
<td>Tel:</td>
<td>0046 850 580 500</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:info@reumatikerforbundet.org">info@reumatikerforbundet.org</a></td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.reumatikerforbundet.org">www.reumatikerforbundet.org</a></td>
</tr>
</tbody>
</table>

## Name and title of President, Treasurer and General Manager/Secretary
- President: Anne Carlsson
- General Manager/Secretary: Annelie Norberg

## Liaison person with EULAR
- Name: Karin Bergstrom
- Email: Karin.Bergstrom@reumatikerforbundet.org
- Tel: 0046 733 689 308

## About the organisation
### Reumatikerförbundet was founded in 1945
The aims of the organisation are:
- Raise awareness about RMD
- Campaign for equal rights & treatment & improve the quality of life for people with RMDs
- Promote contacts with fellow patients
- Support research by fundraising

All types of RMDs are represented by the organisation with branches nationwide. 60-65 members of staff are in the head office & branches, supported by volunteers with RMD.

The organisation counts about 50,000 members.
Activities & Programmes

The most important topics in the coming years are:

- Develop the value of the membership; strengthen the public image of our organisation; develop the structure on local & regional levels; follow & advocate for better conditions in the health care structure; develop the fundraising research; To use patient research partners in the cooperation with the researchers; cooperate with the PARE associations in the Nordic Countries; Run an international cooperation project together with people with RMDs & rheumatologists in Sri Lanka; develop relations with the Swedish MEPs in the EU in order to use their influence in European work; develop our activity in EULAR

Skills the organisation could teach:

- Training: Fundraising, self-management, media, special training for young people/parents
- How to: work in the political arena, plan & run campaigns, work successfully with industry, run EU projects
- Raising awareness about the importance of exercise
- Experts in editing informative brochures and magazines

Skills the organisation would like to improve:

- Need to define better target groups of organisation
- To strengthen the public image of the organisation
- To use patient research partners in the cooperation with the researchers

Youth activities

Age groups represented: 7-32 years
Contact: Madeleine Beerman Chairperson
Email: madeleine.beermann@ungareumatiker.org
Tel/Skype: 0046 739 594 921
Website: www.ungareumataiker.reumatikerforbundet.org

Youth Organisation & Structure

There is an independent youth organisation comprising over 1000 members between 7-32 years old. They have an office with one employee.

Youth Activities & Programmes

The organisation is offering support and information, website, courses and conferences.
RLS – Rheumaliga Schweiz
Swiss League Against Rheumatism

Address of the organisation

Street: Josefstrasse 92
City/Town: Zürich
ZIP/Postal Code: 8005
Country: Switzerland
Tel: 0041 444 874 000
Email: info@rheumaliga.ch
Website: www.rheumaliga.ch

Name and title of President, Treasurer and General Manager/Secretary

President: Franz Stämpfl
Treasurer: Kurth Birri
General Manager/Secretary: Valerie Krafft

Liaison person with EULAR

Name: Valérie Krafft
Email: v.krafft@rheumaliga.ch
Tel: 0041 444 874 000

About the organisation

RLS was founded in 1958

The aims of the organisation are:

- Elaboration of a strategy for non-communicable diseases with other organisations
- Collection of data for prevention procedures
- Focussing on people’s needs of well-being, freedom from symptoms and quality of life
- Defining different services such as leaflets, internet and events

There are 26 regional leagues against rheumatism and 6 national patient organisations.
RLS – Rheumaliga Schweiz
Swiss League Against Rheumatism

Youth activities

Age groups represented:
- Children up to 12 years and “teenagers”
- 15–40 years

Contact: Danica Mathis
Email: d.mathis@jungemitrheuma.ch
Website: www.jungemitrheuma.ch

Youth Organisation & Structure

- 2 national events per year (lecture and exchange)
- Workshop for parents and their children
- Regional communities
Türkiye Romatizma Dernegi
Turkish Rheumatism Society

Address of the organisation
Street: No. 101 K. 7 yason /s. Merkezi
City/Town: Istanbul
ZIP/Postal Code: 80600
Country: Turkey
Tel: 0090 212 247 504 7
Email: ndilsen@yahoo.com.tr

Name and title of President, Treasurer and General Manager/Secretary
President: Prof. Guzin Dilsen
Treasurer: Banu Ergezen
General Manager/Secretary: Prof. Nihat Dilsen

Liaison person with EULAR
Name: Prof. Nihat Dilsen
Email: ndilsen@yahoo.com.tr
Tel: 0090 212 247 504 7

About the organisation
Türkiye Romatizma Dernegi was founded in 1977
The organisation is run by the Executive Committee which is composed of 5 members: President, Vice-President, Secretary, Treasurer and a board member.
Membership is open to: Physicians, health professionals, people with rheumatic and musculoskeletal diseases (RMD).
### Activities & Programmes

The main aims of the Society are:
- To participate in the activities of and cooperate with EULAR and the PARE organisations
- Participate in worldwide activities to raise awareness about RMDs
- Raise awareness about RMDs in Turkey
- To give advice and help to the people with RMDs in different ways

### Youth activities

No youth activities at present.
ARMA - Arthritis and Musculoskeletal Alliance

Address of the organisation

- **Street:** 18-20 Bride Lane
- **City/Town:** London
- **ZIP/Postal Code:** EC4Y 8EE
- **Country:** United Kingdom
- **Tel:** +44 (0) 20 7842 0910
- **Email:** info@arma.uk.net
- **Website:** www.arma.uk.net

Name and title of President, Treasurer and General Manager/Secretary

- **President:** Dave Marsh
- **Treasurer:** Chris Dicks
- **General Manager/Secretary:** Federico Moscogiuri (CEO)

Liaison person with EULAR

- **Name:** Anoushka Lyen
- **Email:** alyen@arma.uk.net
- **Tel:** +44 (0) 20 7842 0910

About the organisation

ARMA is the umbrella body providing a collective voice for the arthritis and musculoskeletal community in the UK and was founded in 1972.

The aims of the organisation are:

- Help shape policy
- Contribute to the transformation of service delivery
- Bring about improvements in the treatment of people with rheumatic and musculoskeletal diseases (RMDs)

We have 40 member organisations, ranging from specialised support groups for rare diseases to major research charities and national professional bodies.

ARMA's vision is of an effective, unified musculoskeletal community working together to improve the lives of people with musculoskeletal disorders (MSDs).

ARMA strives to transform the quality of life of people with musculoskeletal disorders. This is achieved by shaping policy and best practice in partnership with its member organisations.

For more information, visit www.arma.uk.net
ARMA - Arthritis and Musculoskeletal Alliance

Youth activities
Age groups represented: All age groups
Contact: Anoushka Lyen
Email: alyen@arma.uk.net
Tel/Skype: +44 (0) 20 7842 0910
Website: www.arma.uk.net

Youth Organisation & Structure
Several of our member organisations work with children and adolescents with arthritis and their parents and carers. They are involved in a wide range of activities across the age groups.
**ASIF c/o Ankylosing Spondylitis Association of Ireland**

<table>
<thead>
<tr>
<th>Address of the organisation</th>
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<tbody>
<tr>
<td>Street:</td>
<td>Carmichael Centre, North Brunswick Street</td>
</tr>
<tr>
<td>City/Town:</td>
<td>Dublin 7</td>
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<tr>
<td>ZIP/Postal Code:</td>
<td>80600</td>
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<tr>
<td>Country:</td>
<td>Ireland</td>
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<tr>
<td>Tel:</td>
<td>0090 212 247 504 7</td>
</tr>
<tr>
<td>Email:</td>
<td><a href="mailto:info@ankylosing-spondylitis.ie">info@ankylosing-spondylitis.ie</a></td>
</tr>
<tr>
<td>Website:</td>
<td><a href="http://www.asif.info">www.asif.info</a></td>
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<thead>
<tr>
<th>Name and title of President, Treasurer and General Manager/Secretary</th>
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<tbody>
<tr>
<td>President:</td>
<td>Mr. Seoirse Smith (Ireland)</td>
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<tr>
<td>Treasurer:</td>
<td>Mr. Rene Braem (Switzerland)</td>
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<tr>
<td>General Manager/Secretary:</td>
<td>Mr. Michale Mallinson</td>
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<tr>
<th>Liaison person with EULAR</th>
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<tbody>
<tr>
<td>Name:</td>
<td>Ms. Debbie Cook (UK)</td>
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<tr>
<td>Email:</td>
<td><a href="mailto:director@nass.co.uk">director@nass.co.uk</a></td>
</tr>
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</table>

**About the organisation**

**The organisation was founded 1988.**

There are 34 member organisations.

Membership is open to organisations with a shared interest and objectives in supporting people living with Ankylosing Spondylitis and related conditions.

Our most recent achievements are the increasing number of national organisations who have joined with us.
European Network of Fibromyalgia Associations

Address of the organisation
Street: Impulsstraat 6 C
City/Town: Heist-op-den-Berg
ZIP/Postal Code: 2220
Country: Belgium
Tel: +44 02088986139
Email: contact@enfa-europe.eu
Website: www.enfa-europe.eu

Name and title of President, Treasurer and General Manager/Secretary
President: Pam Stewart
Treasurer: Joop van Griensven
General Manager/Secretary: Ella Vine
Vice President: Souzi Makri

Liaison person with EULAR
Name: Pam Stewart
Email: president@enfa-europe.eu
Tel: +44 02088986139

About the organisation
The aim of ENFA is to promote Fibromyalgia awareness to politicians, physicians, scientists and the general public at a European level

As Fibromyalgia has been recognized by European politicians through the written declaration 69/2008. It is for ENFA to get the written declaration into action with a primary goal to get Fibromyalgia as a key topic in the European Health Programme.

In order to realize the goal ENFA is working in a three pronged manner.

• ENFA has to work together with sister associations in order to get a bigger voice in Europe.
• ENFA has to work together with other European umbrella associations to get more involved in the policy making process.
• ENFA has to strengthen the association by way of increasing membership.

A committee is elected from its members who are all national organisations representing people with fibromyalgia. They are all volunteers and have a part time secretary sponsored by one of the organisations.

Activities & Programmes
Members of ENFA have attended EULAR and PARE conferences in Rome and Paris and the Pain Alliance Europe and European Patient Forum meetings.

We also provided a patient voice for the committee deciding on the update of the EULAR guidelines on fibromyalgia.

A pan European survey is being run in 2015 to gather information about fibromyalgia throughout Europe, including treatment options and effectiveness.
Federation of European Scleroderma Associations aisbl. - FESCA

Address of the organisation

Street: FESCa aisbl le Versailles 20/32 avenue des Etats unis
City/Town: Tournai
ZIP/Postal Code: 7500
Country: Belgium
Website: www.fesca-scleroderma.eu

Name and title of President, Treasurer and General Manager/Secretary

President: Ann Tyrrell Kennedy
Treasurer: Despo Charalambous Demetriou
General Manager/Secretary: Alexandra Portales

Liaison person with EULAR

Name: Ann Tyrrell Kennedy
Email: anttkennedy@gmail.com
Tel: 0035 312 846 080

About the organisation

FESCa aisbl. was founded in June, 2007

FESCa aisbl. has currently 23 member organisations from 18 countries, and two countries applying for membership.

Membership in FESCA aisbl. is open to any national organisation that offers support to those who have scleroderma. Such an organisation can also provide support to those with mixed connective tissue disease, Raynaud’s, or lupus. No more than two organisations can join from any one country.

Aims and objectives of the organisation are:

- To achieve earlier diagnosis and better treatments
- To create greater awareness of scleroderma
- To develop parity of care and treatment throughout the EU

- To do this, FESCA aisbl. facilitates collaboration among national associations to share ideas and projects, and works towards the evolution of a – political, – social, and – medical environment

that facilitates the achievement of the FESCA aisbl. vision
Activities & Programmes

Our recent achievements have been:

- To create and develop World Scleroderma Day, with global use of an iconic painting by Paul Klee, on June 29, the day on which Paul Klee died of scleroderma.
- To develop a World Systemic Sclerosis Congress.
- To develop a biennial mid-career-rheumatologists’ training course in SSc.
- To more than triple the number of organisations that are members of FESCA aisbl, since its founding in 2007.

To develop in a very short time an identity that is recognized throughout the world as representative of patients, and is respected as the voice of patients in Europe.

- To apply for and be established as one of 14 partners in an EC 7th Framework Programme For Research And Technological Development, the biggest project ever sponsored by the European Union for systemic sclerosis, “The DeSScipher Project”.
- To participate in numerous research programmes to ameliorate care of scleroderma patients, such as SPIN, EUSHNET, BURQUOL-RD, etc.

The biggest challenges in the coming years will be:

- To establish sufficient funding to support research into new treatments.
- To establish parity of care in Europe.
- To reach every scleroderma sufferer in Europe.
- To run a successful World Scleroderma Congress that is open to patients from around the world.

Is there a youth group or organisation for youth? NO, although some national organisations (e.g. RSA in the UK) do have programmes for young people.
# Lupus Europe

## Address of the organisation

<table>
<thead>
<tr>
<th>Street</th>
<th>St. James House, Eastern Road</th>
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<tbody>
<tr>
<td>City/Town</td>
<td>Romford</td>
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<tr>
<td>ZIP/Postal Code</td>
<td>RM1 3NH</td>
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<tr>
<td>Country</td>
<td>UK</td>
</tr>
<tr>
<td>Tel</td>
<td>+45 21406005</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:chair@lupus-europe.org">chair@lupus-europe.org</a></td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.lupus-europe.org">www.lupus-europe.org</a></td>
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## About the organisation

**Vision:**
A fulfilling life for all people with lupus in Europe until we have reached a world without lupus

**Mission:**
To be the voice of lupus in Europe and empower the national organisations for people living with lupus

**Strategic Drivers 2013–2017:**
1. PEOPLE with lupus in Europe participate in and benefit from lupus research
2. Member organisations are enthusiastic and empowered
3. LUPUS EUROPE is heard and acting

## Name and title of President, Treasurer and General Manager/Secretary

<table>
<thead>
<tr>
<th>President</th>
<th>Kirsten Lerstrøm</th>
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<tr>
<td>Treasurer</td>
<td>Alain Cornet</td>
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<tr>
<td>General Manager/Secretary</td>
<td>Anne Charlet</td>
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<tr>
<td>Vice-Chair</td>
<td>Blanca RUBIO, Kirsi Mylyls, Kathaine Wheeler</td>
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## Liaison person with EULAR

<table>
<thead>
<tr>
<th>Name</th>
<th>Kirsten Lerstrøm</th>
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<tbody>
<tr>
<td>Email</td>
<td><a href="mailto:kirsten@lerstrom.dk">kirsten@lerstrom.dk</a></td>
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<tr>
<td>Tel</td>
<td>0+45 21406005</td>
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Lupus Europe

Activities & Programmes

Strategic drivers for 2015:

People
- Active involvement in establishing an international registry for lupus
- Support patients’ participation in research activities leveraging member groups

Members
- Information on lupus and member organisations collated and available for publicly sharing
- Organisational support (e)-available (best-practice, online tools, guidelines)
- Stimulate knowledge development via patient participation in projects

LUPUS EUROPE
- Volunteer and pro-bono capacities mapped for a bank of resources
- Web portal increased
- Globally, ensuring patients’ event at International Congress for Lupus

Youth activities

Age groups represented: 18-35
Contact: Jeanette Andersen
Email: Cats97@gmail.com
Tel/Skype: jeannette.andersen53

Youth Organisation & Structure

At LUPUS EUROPE Convention 2014 was the first time “Youth” was addressed.

Among the participants, the young people’s initiative was to create cross-border cooperation among national lupus groups, to share good practices and to exchange experiences. It is necessary to address the possibilities and obstacles for education and work for young people with lupus.

The structure of the Youth part of LUPUS EUROPE is yet to be decided.

Youth Activities & Programmes

Among activities, it is the aim of the young people to have better access to treatment. This can be reached through information on the outcomes of research in lupus, through information obtained at LUPUS EUROPE Conventions, through publications of lupus organisations and empowerment of young leaders through targeted trainings and workshops.

Some of our young member are also Patient Research Partners that could lead to them giving workshops on the progress of lupus research.

LUPUS EUROPE will support networking among member organisations as well as sharing good practices through its members area on the website.