

EULAR EDUCATIONAL VISITS PROGRAMME 2011

SERBIA - GERMANY

ESSEN
20-23 October 2011

REPORT

Deutsche Rheuma Liga Nordrhein-Westfalen e. V.

&

The Association of Rheumatic Diseases Patients of the Republic
of Serbia



Every year the European League Against Rheumatism (EULAR) funds educational visits amongst EULAR PARE member organisations. This year, 2011, the Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS) applied for a part of these financial resources. To our great pleasure, the project was approved in June this year. Through previous contacts with Deutsche Rheuma Liga Central Office it was agreed that the

- Teaching organisation will be:
Deutsche Rheuma Liga Nordrhein-Westfalen e. V. Branch (DRLNW), and the
- Learning organisation will be:
The Association of Rheumatic Diseases Patients of the Republic of Serbia (ORS)

The educational visit took place in Essen and Duisburg, Germany from 20 - 23 October 2011. Serbian delegation included Mirjana Lapcevic, ORS President, Marija Kosanovic ORS Vice President and Marija Bucic, ORS Medical Military Academy Branch President, as well as Bojana Vlajsavljevic, German/ Serbian interpreter.

The main aims of the visit were to:

- gain insight into the structure and workings of a successful, mature sister organization, and in particular into:
 - the systems and protocols for an efficient administration process
 - financial management tools
 - development of annual and longer term plans
 - methods of evaluation,
- gain insight into the operation of branches and their dynamics with central office,
- learn how to attract, engage and grow human resources and membership base,
- develop relationship and collaborative links with a sister EULAR organisation.

Our German hosts offered an excellent, comprehensive and varied programme (included as Attachment A to this report).

The two organisations agreed in advance to start the first day of the visit with a general presentation about each association and look at their similarities and differences, as well as each suggest their expectations from the visit.

The second day included a trip to a local organisation in Duisburg, where Serbian guests could gain first hand insight into the workings of a local Branch of Deutsche Rheuma Liga.

The third day of the visit was devoted to in-depth discussions with the members of the DRLNW Executive Board as well as the members of the local Branch in Essen. Our kind German hosts also took us to meet with representatives of their close partner organisations.

In comparing the Executive Board structures, we have found that DRLNW one is not only larger in numbers (19 to ORS' 5) but also more varied and encompassing, as it includes several key organisations of the German health system. The significance of these inclusions was not lost on us, and we will be looking to expand our Board by attracting key players in the Serbian social and health system in the shortest possible timeframe. One other important difference has been that in ORS, both Strategic and Executive Board consist of volunteers only, whereas in the teacher organisation, DRLNW, the situation is quite opposite, they employ 13 staff. Of course, what also needs to be taken into account is that ORS is a fledgling 4 year old compared to its system organisation in Essen that was founded 37 years ago. It will take some more time for ORS to reach a stage where it can actually employ a person in its own right.

We have also discovered that Deutsche Rheuma Liga is based on self-help organisations. This means that it is members first and foremost that are engaged in education and in providing assistance and help to other people suffering from rheumatic diseases. The members also take on a much more active role and responsibility in improving the quality of their own lives. This has led us to the conclusion that we must work harder on increasing the awareness of people with rheumatoid diseases, and generally any others suffering from other chronic illnesses, that they need to be in the driving seat. They need to take charge and start to actively participate in their treatment and actively improve their quality of life. As its long-term goal, ORS should start creating and facilitating a network of special groups within Branches where our members would meet and socialise, exchange their experiences but also have fun. Those could include walk groups, reading groups, cinema-lovers, people who enjoy exercising in nature, etc.

The breadth, significance and value of Deutsche Rheuma Liga is perhaps best understood through a project entitled "Functional Therapies" that has been funded over a number of years by the German Social Insurance and Pension Fund. Over 30,000 people with musculoskeletal diseases have been able to attend exercises twice a week, funded by the Government but lobbied, organised and delivered through Deutsche Rheuma Liga in Northern Rhine and Westphalia. Both have recognised the importance of prevention as well as reduction in diseases' symptoms and their consequences. As our German colleagues have pointed out, a Swiss study has shown that each euro invested in prevention and rehabilitation will be returned within four months. ORS will now focus its efforts strongly into increasing the visibility and importance of projects that improve physical activity and keep the rheuma sufferers in employment for longer, which should, in a cascading effect, also reduce the stress on government coffers.

It was in the Duisburg Branch of DRLNW that we have witnessed the importance of cooperation between medical practitioners – rheumatologists and the association. The office of this Branch is located at a clinic 'Duisburg Klinikum' in Duisburg, and strongly underpinned by relevant posters and stands located in very visible places within the Rheumatology Department of the hospital. DRLNW being such a strong association of patients as it is, is also very helpful to rheumatologists there. They work in great symbiosis, which is evidenced by the fact that Germany has a smaller number

of rheumatologists per capita than Serbia does. It is very clear to us that a greater cooperation between rheumatologists and ORS would assist ORS to increase its membership base on one hand, with patients turning more to ORS for help and advice, and on the other hand, reducing the pressure on rheumatologists. In Serbia, we plan to improve ORS' communication with medical professionals by direct contact 'face to face' between our activists and rheumatologists, and increase medical experts' awareness of the importance and usefulness of ORS to both them and their patients.

In the next 12-month period we will also focus on improving the communication between ORS Executive Committee and its branches. Our colleagues from DRLNW have kindly provided us with their documents that regulate the relationship between the central office and its local branches. We will be creating similar documents for ORS with clearly defined obligations and responsibilities of the branches (for example, each branch would be required to have a minimum of two general meetings per year). In a year's time, we are hoping to be able to measure the effects of these improvements in central office – branches dynamic.

On suggestion from our hosts, we have started considering a project called 'Patients Partners'. A presentation on the idea and philosophy behind this project was provided to us by Mr. Karl Katlens. The project provides for patients to meet and talk with young medical students and doctors starting their specialised studies in rheumatology, enabling the medical professionals to see and hear first hand experiences, symptoms and suffering of their rheuma patients before they start to practice. Mr. Ulf Jacob, DRLNW Manager, has suggested investigating if Pfizer pharmaceutical company would be interested in funding a similar project in Serbia. We are very keen to get this project off the ground as it would have a multi-layered effect on the quality of medical treatment of people with rheumatic diseases in our country. The education of doctors by patients would definitely improve the relationship between the two and enhance doctors' understanding and relationship with their patients, but would also increase the patients' awareness and understanding of their doctors. Doctors 'educated' in this way would be able to recognise the symptoms of rheumatic diseases more readily, which would significantly reduce the time from the appearance of first symptoms to the correct diagnosis. This project would also benefit the government institutions as this very useful 'education' would be financed by a third party.

On our return from this visit to our German colleagues, our number one priority will be to transfer the gained knowledge and experiences to our Branch executive teams and all ORS members, but also to rheumatologists, Government Departments and Institutions and Social Insurance and Pension Fund representatives. In parallel to communicating all that we have seen and heard, of great importance will also be to translate all relevant documents that have been made available to us through the kindness of our hosts. This would then lead into re-writing of rules and regulations that govern the work of ORS and a change in the way ORS is structured. In keeping with what we have seen, it is crucial that our branches become more active and engaged and start to bring local members together and interact with them. This, in turn, would allow the ORS Executive Board to work on a higher, strategic level, lobby harder, engage the media more often, educate the public more forcefully and generally

lead the way and develop projects of importance to all sufferers of rheumatic diseases in Serbia.



From left to right:

Ulf Jacob, Marija Bucic, Brigitte Killewald, Mirjana Lapcevic, Marija Kosanovic, Hildegard Mang, Bojana Vlasisavljevic and Bettina Teutenberg.

We would like to thank The European League Against Rheumatism for enabling us to undertake this educational visit. We would also like to thank Deutsche Rheuma Liga and in particular our colleagues in DRL's Northern Rheine – Westphalia Branch who gracefully accepted to be our teachers and hosts. Last but not least, we would like to thank all the staff, in particular Ulf Jacob and Bettina Teutenberg, and volunteers of Deutsche Rheuma Liga and their partner organisations, who have made this visit not only informative and instructive, but also very enjoyable and one we will never forget.

Marija Kosanovic
Vice-President
For The Association of Rheumatic Diseases Patients
of the Republic of Serbia (ORS)

Attachment A: Visit Programme, as put together and organised by our gracious hosts at DRLNW

Attachment A

Deutsche | RHEUMA-LIGA
Nordrhein-Westfalen e.V.



www.rheuma-liga-nrw.de

EULAR's Educational Visits Programme Project
Association of Rheumatic Diseases Patients of the Republic of Serbia
visit Deutsche Rheuma-Liga Nordrhein-Westfalen
from Thursday 20th October 2011 to Sunday 23rd October 2011

Time Schedule

Thursday, 20th October 2011

- 10.15** **Düsseldorf Airport**
Flight: LH529 V 20OCT BEGDUS 0805 1015
Escort: Bettina Teutenberg
- 11.28 Regional Express(RE10119)
from Düsseldorf to Essen railway station
departs at platform 1
(way to the hotel about a 20-minute-walk)
- 12.15** **Check in: B&B Hotel Essen**
Helmut-Käutner Straße4
45127 Essen
- 13.15** **Lunchtalk**
Joint lunch at
Church Restaurant (www.church-essen.de)
III. Hagen 37; 45127 Essen

Meeting Point: Office of
Deutsche Rheuma-Liga NRW
III. Hagen 37; 45127 Essen
(Way to office about a 10-minute-walk)

Escort: Ulf Jacob, Bettina Teutenberg
(Executive Management)
- 14.00** **Expectations and first introductions**
Expectations of the visit
What bits of information are you interested in?
What subjects are important to you?
Differences and sameness of "self-help-identity" in both countries
Structure and work of both associations
Executive management

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- 15.30** **Deutsche Rheuma-Liga NRW in practice**
 The office and different departments of Deutsche Rheuma-Liga NRW
 Talk with some employees of the office
- 17.00 **Time-out**
- 19.00 **Exploring Essen / Dinner**
 Escort: Dieter Wiek (President); Brigitte Killewald (Member of the managing committee)

Friday, 21th October 2011

- 09.03 Departure from "Berliner Platz" in Essen
Plattform 2 / Underground U 11 direction Essen-Messe W.-Süd Gruga
(way from hotel to the station about a 5-minute walk)
- 09.15 Departure from Essen railway station to Duisburg
Plattform 7 / S-Bahn S1 direction Solingen Hbf
- 09.47 Duisburg Schlenk Bahnhof
Bus 944 direction Duisburg Wolfsee
- 09.51 Duisburg Klinikum (Hospital)
(way from station to the hospital about a 5-minute-walk)
- 10.00 A local organization in practice
Talk with the volunteers of the local organization in Duisburg
Organization of the "Arbeitsgemeinschaft"
Cooperation with rheumatologic departments in hospitals
Volunteers of Arbeitsgemeinschaft Duisburg**
- 12.26 Departure from "Duisburg Klinikum" to Duisburg railway station
Bus 934 direction Duisburg Bertr. H. am Unkelstein
- 12.40 Departure from Duisburg railway station to Duisburg Schwanentor
Exit east - Plattform 2 / Bus 933 direction Duisburg Rheindeich
- 12.50 Arrival Duisburg Schwanentor (harbour)
- 13.15 Boat Tour**
Talk with volunteers of the Arbeitsgemeinschaft Duisburg
during a harbour boat tour
(Alternative: [staying at the hospital](#))
**What do volunteers expect from the association?
Motivations of volunteers**
Volunteers of Arbeitsgemeinschaft Duisburg
- 14.30 Arrival at Duisburg Schifferbörse
- 14.48 Departure from "Duisburg Scharnhorststraße" to Duisburg railway station
Tram 901 direction Mülheim Hbf
- 15.00 Departure from Duisburg railway station to Essen
Plattform 8 / Regional Express RE11 direction Hamm (Westf.)
- 15.21 Departure Essen railway station
Plattform 1 (outside) / Tram 101 direction Germaniaplatz
- 15.25 Arrival Essen Berliner Platz
- 15.30 **Time-out**
(Dinner)
- 18.30 **Meeting point: Office**

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19.30 Aalto theatre Essen
Ballet Carmen / Bolero
(<http://www.aalto-ballett-theater.de/wiederaufnahmen/carmen-bolero.htm>)
Escort: Karin Gros-Dybowski, Gabriele Kamann, Elvira Orlov (employees)
22.00 Back to the hotel

Saturday, 22th October 2011

- 11.00 Practice Talk**
with members of the managing committee
Structure of the managing committee
Questions and answers.
Office of Deutsche Rheuma-Liga NRW
Dieter Wiek (President); Alexander Flüthmann (Treasure);
Brigitte Killewald; Hildegard Mang; Barbara Markus
Volunteers of the managing committee
Ulf Jacob
Executive manager
- 13.00 Lunchtalk**
Joint lunch at
Church Restaurant
- 15.00 Practice Talk**
with the volunteers of the local organization in Essen
Organization of the “Arbeitsgemeinschaft”
What volunteers do expect from the association?
Motivations of volunteer involvement.
Cooperation with other “self-help associations
Volunteers of Arbeitsgemeinschaft Essen
Volunteer of the office of self-help „die Wiese“ Essen
Escort: Brigitte Killewald, Hildegard Mang
- 17.00 Coffee talk**
Final talk
Did you get all information you wanted?
What is your impression?
Last questions and answers
Office
- 18.00 Time-out**
- 19.30 Exploring Essen / Dinner**

Sunday, 23th October 2011

Experience the “Ruhrgebiet”

http://essen.de/en/Aktuell/PortalAktuell_E.jsp

A possible programme could be:

11.00-13.00 City tour Essen

<http://www.essener-stadtrundfahrten.de/index/getlang/en> or

Price: 13,00 € per person

Folkwang museum Essen

<http://www.museum-folkwang.de/en/exhibitions.html> or

Zeche Zollverein with Ruhrmuseum Essen

http://www.zollverein.de/english/index.php?f_categoryId=3 or

Old Essen Synagogue

<http://www.essen-fuer-das-ruhrgebiet.ruhr2010.de/en/programme/re-designing-the-metropolis/structural-culture/old-essen-synagogue.html>

15.09 Depart from Essen railway station
Platform 2 / Regional Express RE 10128

15.31 Arrival Düsseldorf Airport

17.20 Depart to Munich
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