

## **Educational Visit of The Hellenic League against Rheumatism to the Norwegian Association of Patients with Rheumatic Diseases. (Sept 2011)**

We were informed about the structure of the Norwegian Association. The Association is one of Norway's largest voluntary organisations. The Norwegian organisation has 37000 members and it set up in a pyramid model. The 250 local branches (3-7 members of board) which are under the 19 regional branches which are as many as the regions of Norway (5-7 members of board) and finally the central office in Oslo (7 members of board; 5 elected, 1 employee, 1 from the youth organisation). The Association is currently proposing of changing their set up, the proposal is going to be voted upon in their general meeting in October. The proposal is to create separate societies based on the different diagnosis of rheumatic diseases and all of these to be under the umbrella of the central office in Oslo.

What was impressive was the number **of full time and part time salaried employees, each one of them was highly qualified and with specific target areas set by the Association.** Another important aspect of the Association is that it keeps a very detailed computerised account of all its actions and of all the data of its members, therefore, the Association has the ability to analyze in depth almost everything. A well planned and organised Association that meets its aims and goals. **A big contrast to our Association, where everything is performed on a volunteer base, with the exemption of one part time salaried psychologist post (funded by a pharmaceutical company).**

We believe that based on the knowledge of our Association it is more appropriate **to have a model of regional branches under the umbrella of the central office.** When the numbers of the Association will increase then the formation of local branches will be in need. The idea of creating societies based on the diagnosis is very tempting but we need many members. **Possibly we could create better bridges of collaboration with societies of other diseases in Greece.**

The Norwegian Association is partly funded by the Norwegian Government, the money given to the Association is based on the number of members. Unfortunately, **the Greek government cannot afford any funding to our association, so we are in the process of investigating possible funding schemes from the other sources.**

The Norwegian Association regarding funding has two goals: to have enough funding for the employees and for their activities. The Norwegian Association is also aware that from the 40000 members that they had few years ago they dropped to 37000, this figure alarmed them and are trying to find means of gaining new members.

**The funding of the Norwegian Association is done by the following means: 1. Funding from the Norwegian government, 2. Membership fee from the members, 3. Lottery, 4 Donations, 5. Selling useful equipment for patients.**

**The Association is trying to motivate its members in subscribing more members by reminding them that if you subscribe one member you get a present if you subscribe more members you get more presents.** The annual membership fee is equivalent to 50 euros. An employee of the Association is collecting the membership fee and keeps all the statistical data regarding the members. If a member has not paid the membership fee then it is reminded by the Association. When a new member joins in the middle of the year then the membership fee is halved.

The lottery project is a scratch ticket that gives out 500000 NK once per year and 10000 NK per week. This card is sold by the Association, it is advertised, it is for everybody and sold wherever it is possible.

**The Association asks for donations from their members and from the whole of Association 4 times a year (autumn, Christmas, Easter and summer).** This is a major project. This is done by letters where they send a prepaid envelop with a cheque, in some cases the amount is not mentioned (this is addressed to people who the Association already knows that give a lot of money, the Association keeps computerised data regarding all donors) and in others the individuals are given a choice of amounts to select. This type of donation is very well organised. The Association decides which targets group to reach, for instance they have the data which show that groups of ladies of the age range that possibly might have a rheumatic disease are good donors. The Association buys all this information from companies that have people's data. In each envelop the Association also includes a small present, i.e. Christmas cards at Christmas time, calendar, notepads. This year the Association has started asking for donation via its magazine, the Association places a postal order in the magazine. During the year the Association reminds for donations discretely, i.e. in funeral homes they have pamphlets where they remind the relatives/friends of the Association and ask for donations. **The Association also receives money from legacies. Some banks are also giving donations from their profits. The money given to the Association from donations are not taxed.**

**Selling equipment over the internet is another source of income.** The Association has different gadgets that are very useful for patients with rheumatic disease and also different accessories with the Association's logo. All these items are advertized and sold via the webpage of the Association.

In the past the Association was also raising money by organizing bazars and raffle tickets.

The Association for its activities is trying to get funded by pharmaceutical companies. The Association's congress **can be funded by pharmaceutical companies up to 50% of its budget.** The Association sets an aim for its activity and then tries to find donors from the pharmaceutical area, from banks, and from whoever the Association believes that might fund their activity.

Recruiting new members is a laborious task. Especially the Association would prefer/target its new members to be of a young age. The people involved with recruitment are trying to find means to attract new members, they try to see what more can the Association offer to its new members and try to demonstrate it, they try to answer questions like why will new members join our Association, they ask their members why they join and the Association analyses their answers in order to gain valuable information. The Association has a webpage on the internet, it is also on facebook and on twitter. People can become members via internet. **Statistical analysis showed that 56% of the new members were recruited via internet and 31% joined by other members.** The idea behind recruiting is simple the Association tries to find why will new members join them and then the Association tries to demonstrate all these reasons to the Norwegian Association. The Association argues that they are the professionals that know in the best possible way the issues regarding rheumatic diseases, they have the scientific data to back up their knowledge, it is in their best interest the well being of people with rheumatic diseases, they know the rights of the patients, they do their best to safeguard and to maximize the rights of the patients and they can give to the people the correct advice regarding their rights, overall the Association offers information that people can trust. Another key point of their strategy is that they argue that the more people join the Association then the stronger is the Association and its voice can be heard louder and this is beneficial for the patients. The ways to demonstrate all these reasons is variable. The Association organises activities/campaigns on important dates they make a press release and organise activities, they distribute information pamphlets. They do meetings together with physiotherapists and the Association shows their points, the Association gives stands and information pamphlets to the offices of physiotherapists. In a similar way they collaborate with pharmacists. The Association also has in the rheumatologic clinics information pamphlets and stands of the Association asking for new members. The local societies are trying also their best to recruit new members, for instance while we were visiting Oslo on the Saturday of our departure the Oslo branch was organising an activity in the town centre in order to recruit new members.

The Association updates as often as possible their information booklets about different types of rheumatic diseases, they are currently thinking of issuing one booklet which will include all types of rheumatic diseases. The Association prints a number of information pamphlets and regularly the design is modified in order to be as new and refreshing as possible.

The Association is well aware of all the newest treatment methods of rheumatic diseases. The Association wants to create a list of patients to whom the biological factors are administered. The Association believes that therapeutic pools of hot water of 37°C is very important and for this reason they **have built a site in Spain where Norwegian patients with rheumatic disease go all year around for treatment...Rheumasol is a fully organised place for the**

**needs** of the patients. The Norwegian government is also funding therapeutic trips to other places with hot water.

The Association prints its magazine 6 times per year and it is send to its members. The magazine can also be found in the Association's webpage but is only accessible to its members. Each issue has a specific issue that it deals with. The main thought of its editor is that every member should be able to find topics that interests them. The set up of the magazine is the same for each issue. There is a letter from the President, diagnostics section, professional guest speakers are writing an article, members of the Association contribute with a short story, a section of the magazine is organised by the juvenile arthritis group, news from the regional and local branches, information on activities.

The webpage of the Association is very good, userfriendly and updated 2-3 times each week. It contains information about the membership, information about the different types of rheumatic diseases, a question part, a selling part, information about seminars, information about the helpline, and information for the rheumasol are only some of the big number of issues that the site is addressing. The site also shows how important is exercise by having a small fitness program installed, the program shows the exercise they should do and the people can set it to remind them regularly.

The Association has a **peer support program**. The definition of peer support is: people with rheumatism and musculoskeletal disorders who have learned to live and deal with their situation, use their own experience in helping and supporting others. The peer support consists of meetings and self-help group and of the national helpline. The helpline is being run by volunteers who have been trained for this special kind of service from the Association. The volunteers are from all over Norway, the call centre is transferred to the branch that is supporting the service on that day and that can be anywhere in Norway. The helpline is working 3 days per week from 9.00-15.00 and it is open to everybody that has questions concerning rheumatic and musculoskeletal disorders. Professional service is received by a rheumatologist from the rheumatologic department of an Oslo hospital. The information on all incoming calls is registered in order to do good statistics. Their statistics underline the need of support to people having diagnoses causing a lot of pain, given limited treatment except painkillers. The peer support offered by the Association is an important supplement to the public healthcare and it fills a need the public healthcare do not have the capacity to accomplish. **The peer support is partly funded by the Norwegian government.**

### ***The Norwegian organisation for children and youth with rheumatism (BURG)***

Burg is part of the Association but it is economically independent and has a board that consists of youth with rheumatism and their parents. Burg has a cutting off point of 26 years of age because the government gives more money for people under the age of 26. Burg has

local branches all over Norway which have their own boards. The local groups try to organise their own activities. The central Burg organises 3 big events: 1. A family summer camp (0-14 years and the rest of the family) they usually go to rheumasol or another city and they have theory lessons for parents, invite guest speakers, give information and examples to teenagers/children on how they can master their problems, at the same time they want the children and their families to have fun. 2 A teenage weekend (13-18 years) usually teenagers go to this event on their own. 3. A youth weekend (12-30 years old). All these activities are held once a year. The rationale behind is that it is better to have a small number of activities which are very good than having too many since the lifestyle is such that people are busy and involved in too many things and they do not have so much free time. Burg has a website ([www.burg.no](http://www.burg.no)).

### **Politics and the Norwegian Association.**

The person in charge of the politics Department is preparing question made at the parliament regarding patients with rheumatic diseases. However they have realised that criticism and questioning is ever more beneficial for the association when posing their question/argument to also have ready their suggestions which can solve according to the association the problem. Their aim is not only to criticise but also to give suggestions/solutions. They try to give priority to the most important questions, not to ask too many questions at the same time, but only the important one or two, because otherwise people will not appreciate all the questions and become bored and not focused. Before the National elections they set a number of questions always with regards patients with rheumatic diseases and they sent there questions to the local branches/people so that they can ask future HPs and know their opinions in order to know who to vote.