



Annual Report 2017

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Reports from the EARLS Members

Date 2018-02-15

Introduction

In 2017, EARLS celebrated its tenth anniversary and the year was marked by the delivery of our most important piece of work to date, the Value of Treatment study, delivered in conjunction with the European Brain Council (EBC) and other significant partners. Never before has there been so much evidence demonstrating the profound economic impact of inadequate diagnosis and treatment of Restless Legs Syndrome (RLS), evidence which can no longer be ignored and which provides opportunities that must be seized across Europe.

EARLS is now a respected partner at both a patient-advocacy level and in scientific groups specialising in RLS. We continue to provide a platform for our member groups, while also collaborating with research groups and we are increasingly active in the European arena as important decisions for neurological illnesses are being taken. Our mission is to provide maximum opportunity for people living with RLS and to work toward relieving the immense burden on patients and their families, and society in general.

In a climate of continued austerity across many European countries, we are extremely grateful for the support we have been provided by a range of critical partners, without whom we would not be able to continue our important work. We hope we can rely on these partners as we move forward.

Our annual report is the vehicle through which we can promote our work, while also demonstrating the diverse range of work being done by our members across Europe. I would like to thank all of our members for their continued dedication to our cause and look forward to increasing our collaborative efforts in 2018 and also in the years to come.



Daragh Bogan, President

Meetings EARLS Executive Board 2017

February, 2017: General Assembly Meeting, Paris



Left to right: Sten Sevborn, Sweden; Pentti Fri, Finland; Robert Parisot, France; Erling Guldbrandsen, Norway; Veli-Matti Riitamaa, Finland; Waltraud Duven, Austria; Joke Jaarsma, The Netherlands; Daragh Bogan, United Kingdom.

- March, June, September 2017: Various general and brainstorming meetings executive board
 - June 2017: Presence during meeting European Academy of Neurology.
 - December 2015: Brainstorming members executive board, Munich
 - Throughout the year, many telephone calls and emails on the topics under discussion/consideration with various board Members
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Possible New Members

We have continued to engage with RLS advocacy groups across Europe and to meet with them to communicate the importance of collaboration, to provide a single coherent voice for RLS patients across Europe.

Existing RLS Groups

Germany – We are very pleased to welcome Mrs Katharina Glanz of the German RLS Patient group as an observer to our 2018 meeting.

Italy – Discussions are ongoing with Professor Luigi Ferini-Strambi, President of Mrs Margherita Fiorenza and Professor Rafaele Ferri.

New Groups, contacts maintained/renewed

Poland – We have renewed contact with Mrs Magdalena Sklarek but unfortunately this has not led to progress. We will now pursue our collaboration efforts through Dr Marius Szieminski, from Gdansk.

Romania – We had a further meeting with Mrs Viorica Cursaru during 2017 but unfortunately this has not led to any noticeable progress, to date.

Portugal – We hope to address the current lack of progress in our efforts with Mrs Ana da Gama, during the 2018 EAN Meeting in Lisbon.

Denmark – We have re-established contact with Prof. Poul Jennum but unfortunately this has not led to any significant progress to date.

Greece – We are continuing to engage and discuss with Dr Giorgios K Sakkas and look forward to working with him in the future.

Japan

We were approached by the Japanese RLS patient organization, requesting the rights to translate the EARLS Patient Survey into Japanese. Permission was granted and the study has therefore been translated accordingly.

New Countries

Starting new patient groups is a labour-intensive and slow process. Although patients have been identified who are willing to work with us in setting up new patient organisations, the reality is that this is not easy, and that the voluntary work demands a level of commitment that is difficult to influence from a distance. We remain confident that even if this takes longer than we want the end result will be better awareness of RLS across Europe.

Representation

In 2017, EARLS was represented at various events and conferences. Below are some examples:

- **June 2017, European Academy of Neurology Congress. Amsterdam.** Patient Awareness Corner. Many contacts made, much information on RLS distributed to scientific community. ~ 8,000 neurologists attended.



- **February, June, September and December 2017, European Medicines Agency.** EARLS participates as Member of the Patients and Consumers Working Party
- **Throughout the year, bi-monthly meetings at the European Brain Council.**
- **June 2017: Final meeting Value of Treatment (VoT) Project at EBC.** Many Members of the European Parliament attending. Prominent data on RLS.
- **June 2017: Presentation of VoT posters, Brussels**
- **July 2017: Presentation of RLS – VoT study in European Parliament**
- **September 23rd, International RLS awareness day**
To mark International RLS Day on 23rd September, we worked with patient advocacy groups across Europe to produce and circulate a coordinated press release campaign. This was supported by the publishing of a series of short videos on our Facebook page, asking people to share the videos with their family and friends.

The videos were translated into six languages and published across EARLS social media platforms on 23rd September to coincide with International RLS Day.



The videos drew attention to the EBC's Value of Treatment study and the cost of poor diagnosis and treatment of RLS and were watched by over 50,000 people across and shared almost 1,000 times. On 23rd September the number of visitors to the EARLS website rose to 470 visitors and on 24th September it had 419 visits. In the week of International RLS Day the EARLS website had a total of 923 visits.

- **December 2017, Munich**

EARLS is an active member of European RLS Study Group. Presentation of VoT outcome

- **Other notable achievements over the past year**

- EARLS is an active member of the Education Committee of the European Academy of Neurology
- EARLS participates in the Scientific Panel Meetings on Sleep Disorders as well as on Movement Disorders at European Academy of Neurology Conferences.
- EARLS is now also member of Panel on palliative care at EAN
- EARLS Board Members have participated in workshops on Pharmaceutical Pricing, Access and Reimbursement for representatives of patient organisations at the London School of Economics.
- Through its EFNA membership EARLS was represented at many other European patient advocacy groups.

- **The Value of Treatment**

- The European Brain Council started this major project in September 2015:
- Based on the data we had available from the major EARLS study in 2013 we submitted a proposal in order to be included in the Study. The Study began on January 27th, 2016, when a kick off meeting was held in Brussels. For the purpose of the Study a working group was formed consisting of several top researchers in RLS as well as Joke Jaarsma, as EARLS representative.
- The project ran from January 2016 to June 2017, at which time a white paper with the results was published. The study has proven to be a major development for the awareness of RLS.
- A major publicity campaign began after July. Details will be presented during the GA meeting.

Finances 2017

During the past year, our financial situation was as follows:

Transfer from 2016	€ 63,272.65
Total new Income, 2017	€ 13,632.68
Total Expenses, 2017	€ 9,899.14
Transfer to 2018	€ 67,005.89

Details of the financial report will be presented during our General Assembly meeting. Of the total sum transferred to 2018, the cost for the VoT study (€ 51,819.46) will be paid in February 2018, including a total of €8,993.46 VAT. The EARLS executive is investigating the possibility to get the VAT re-imbursed.

Out total remaining working capital is therefore €15,186.

External appointments

As of January 2018, Joke Jaarsma has been appointed treasurer and member of the executive board of the European Brain Council.

AUSTRIA - DACHVERBAND RESTLESS LEGS ÖSTERREICH

- Relaunching of Websites and Folder
- Employee acquisition to find additional employees for further support groups.
- Austria-wide visits of support groups.
- Organising lectures
- Participation in national and international summits



Members of the Viennese patient group on RLS Day

FINLAND - LEVOTTOMAT JALAT – RESTLESS LEGS RY



Levottomat Jalat-Restless Legs ry is a member association of the Finnish sleep organization Uniliitto ry.

The purpose of the association is to defend the interests of its members as well as all other Finns suffering from Restless Legs Syndrome/WED. The association aims at promoting the quality of life of its members and their family, as well as a sense of parity for RLS patients as citizens.

In order to reach its goals, the association works in a proactive way to protect and develop the access by RLS/WED sufferers to treatment, rehabilitation and other services.

The association encourages the persons suffering from RLS/WED and daytime fatigue, as well as their loved ones/family, to act individually, as a citizen on a national level. The association provides training, information, advice, and other services. The association supports its members' cohesion through social interactions, as well as recreational and cultural activities.

MAIN EVENTS

Information & lecture: Our annual happenings for bigger audiences are “Alertness Week” in spring, and “National Sleepweek” is an autumn event for healthcare specialists. Also “Seven Sleepers Day” at 27.7. and Patient’s rights day in April are examples where information about RLS/WED is shared or lectured for different kind of audiences.

And of course, International RLS/WED Awareness Day 23th of September is a larger information campaign.

Feedback from the patients. We still constantly get feedback from the patients that people in healthcare are not familiar with RLS. One of the main goals of the Finnish Levottomat Jalat-Restless Legs is to get knowledge for healthcare professionals so that people throughout the country could get the right kind of help from their local healthcare services.

RLS peer group has gathered 8 times in 2017 and new RLS-Facebook-group has gathered over 600 members.

Finnish RLS/WED society co-operates (for example) with Finnish Sleep Research Society and sleep disorder clinics.

FRANCE – ASSOCIATION FRANCE EKBOM

JAMBES SANS REPOS



- **AFE General Meeting** – May 2017 – in Paris - gathers more than 100 members.
 - It was the 1st GM of our new President, Robert Parisot.
 - All complicated administrative tasks due to the change of the location from Strasbourg to Paris have been done as well as the reworking of our status.
 - We have had a presentation of Dr. Marie-Françoise Veccherini, Neuropsychiatrist in Paris. She explained that 2017 offers a wealth of information regarding RLS.
 - The French Society of Research and Sleep Medical Care has noted that the RLS was still not considered as a real clinical pathology by some, that the diagnose is very difficult due to the absence from objective criteria and that is often not assumed responsibility for ailment.
 - They have decided to realize a congress on the subject.

- AFE Executive board participate to a “Round Table” under the subject “ Understanding the pathology for a better management of the treatment”
 - Participants of this talk were: Professors Christelle Charley-Monaca, Yves Dauvilliers, Dr. Laurène Leclair-Visonneau and Christophe Petiau.

- More than 10 information meeting on RLS – for public people - have been organized in France during 2017.
- In September, all our correspondents (25) were invited to the annual meeting in Paris.
- In November, AFE Executive board was present in Marseille for the Sleep Congress. During this event they met the Scientific Committee. This meeting was necessary to reinforce the way of working together on a better and efficient way. This exchange has been particularly successful; Our CS goes to send us Documents, publications etc. on the advancement of the research on the RLS to the child etc.
- Prof. Pascal Derkinderen who dismiss from the function of chairman of our CS due to health reason will be probably replaced by Prof. Yves Dauvilliers (we are waiting for confirmation)
- In 2017 the members of France Ekbom Association is 2'200 people.

NORWAY - Foreningen Rastløse Bein, FRB



The Norwegian patient group for Restless Legs Syndrome (**Foreningen Rastløse Bein, FRB**) has been active since 2006. At the end of 2017 the group had 426 paying members. FRB members receive our printed bulletin, *Maurtua* which is issued two times a year, as well as other written information on RLS and on our different information activities. Also, more than 1300 persons are registered as members of our RLS support group in social media (Facebook).

The General Assembly was held in Oslo on April 25th, 2017 and the following board was elected:

Leader: Britt Berntsen

Board members:

Helen Olsen
Berit Caroline Egseth
Inger Østern
Guro Gravem Johansen

Vara members:

Dagrun Fikkan Slørdal

Bjørn Eirik Tindvik

Election committee:

Erling E. Guldbrandsen and Agnar Ryan

In winter 2017 E. E. Guldbrandsen stepped in as representative in the EARLS group after Britt Berntsen and participated in the EARLS meeting in Paris on 11–12 February.

Before summer 2017, Bjørn E Tindvik retired from his position as vara for the board.

During 2017 there has been 3 ordinary **board meetings** and 2 working board meetings. The main activity of the board consists in planning information activity towards the public and in applying for financial support from various kinds of fundings – both in public health care system and in private foundations. Each paying member of the FRB declenches a restricted amount of financial support from the Norwegian health department. Apart from that, it seems to have become increasingly difficult to raise money from other kinds of sources in recent years.

As has been the case for several years, the board is buying professional services from the company, **Orgservice** concerning certain secretary functions, accounting, writing of applications for funding, administration of members' register, arranging of general assembly, and printing of *Maurtua* and other written information material.

As always, the **International RLS day** on 23 September was marked with distribution of information material to the public. Members of the board, and B. Berntsen in particular, were giving information on public stands in Oslo. In addition this year, the great **Value of Treatment Report** (VOT) from EARLS was given particular attention.

Our printed bulletin, ***Maurtua*** (*The Anthill*) is now offered both electronically and as a magazine printed on paper. Britt Berntsen is editor-in-chief, with editorial support from E Guldbrandsen and from Orgservice.

Around 1300 persons are now registered as members of our **RLS support group** in social media (Facebook). Until recently we have also been running a Facebook page with information about RLS but during recent years the Facebook group has been prioritized.

The **Facebook group** is turned into a very active and useful forum for discussion and sharing of experience and support on RLS and PLMD symptoms and treatment. As a matter of fact, during the last couple of years much of the FRB's main activity seems to have been relocated from actual social arrangements and information meetings over to the Facebook forum.

Given the special nature of RLS symptoms and their connection to insomnia, very much of the communication between group members is in fact taking place during late night, right up to the early morning hours. After careful discussion among board members, explicit rules for confidentiality have been established. Also, it is now clearly stated that questions concerning individual medical treatment and the like is not a matter to be taken care of by lay members of the group, so group members are referred to professional medical personnel in this regard.

With the advent of social media and new communication channels in today's media situation the roles and arenas for the FRB patient group are under rapid transformation.

UNITED KINGDOM – RLS-UK



Aim and purposes

RLS-UK was set up as a support group almost twenty years ago to provide advice and support to people living with Restless Legs Syndrome. Today we are a registered charity but we still operate as a team of volunteers and we receive no government funding. Our scope now also includes Periodic Limb Movement Disorder, which accompanies RLS in 80% of cases. RLS-UK / Ekbom Syndrome Association is a registered charity in England and Wales (registration number 1140744). Our mission is to raise awareness of RLS; to provide information and support to those living with RLS; and to improve the quality of RLS care in the UK.

Achievements and Performance

We have continued to grow and to raise awareness of RLS and have achieved and exceeded most of the objectives we defined at our last AGM, these being:

- To increase our social media presence further, with an ambitious target of 20,000 Facebook followers by September 2017.
- To circulate our tri-fold leaflet and A4 poster to 1,000 medical centres across the UK.
- To look at the possibility of a new AGM venue for our 2017 meeting.
- To look at new ways of fundraising to ensure the continued sustainability of the charity.

We will address the outcome of each of these objectives individually:

- 1. To increase our social media presence further, with an ambitious target of 20,000 Facebook followers by September 2017:** While our number of Facebook followers has increased by 50% since our last AGM (from 8,000 to over 12,500), we started to encounter diminishing returns on our advertisements to attract more followers. Because of this we felt additional spending would be inefficient and ineffective. Nevertheless, the number of Facebook followers continues to grow at a rate of 25-30 people a week.

Our new website, launched in February 2017 has been visited almost 60,000 times, 34% of these visitors having been directed to us by the NHS. Our Facebook page and online forum (7,150 members) remain the largest and most popular RLS social media channels in the world.

- 2. To circulate our tri-fold leaflet and new A4 poster to 1,000 medical centres across the UK:** Our new leaflets have been produced and we have secured the addresses of 3,000 medical centres across the UK. Following our 2017 AGM we will send a digest of the meeting to these medical centres so they understand and appreciate the level of patient and professional engagement we have achieved. We will also offer to send leaflets for display in their surgeries.
- 3. To look at the possibility of a new AGM venue for our 2017 meeting:** We looked into this but the cost of travel and accommodation for all of the trustees and guests would be prohibitive. We also asked on social media for help to secure free venues not only for our AGM but also for regional coffee mornings but we received no responses. We remain keen to hold our AGM in the north of England but will not be able to do so until we secure a free venue (which would offset many of the associated travel and accommodation costs).
- 4. To look at new ways of fundraising to ensure the continued sustainability of the charity:** We have continued to explore new funding avenues and have seen a significant increase in membership numbers, which in itself has bolstered our funding.

This has been an incredible year for RLS-UK and awareness of RLS continues to grow, but there is much work still to be done. Our focus for 2017-18 will be on medical professionals and helping to deliver better patient outcomes through stronger collaboration with patient organisations and the NHS.

Structure, governance and management

The method of appointment of RLS-UK trustees is set out in the RLS-UK Constitution. All those who use our services are encouraged to stand for election to the RLS-UK Board of Trustees and we would welcome new applications. The RLS-UK Board of trustees is responsible for making decisions on all matters of general concern and importance to the charity including deciding on how the funds of RLS-UK are to be spent.

Administrative information

RLS-UK trustees until the date this report are:

Mr. Daragh Bogan, Chairman

Miss Ellie Macdonald, Treasurer

Mrs. Beverley Finn, Helpline Coordinator

Mrs. Monica Twamley, Membership Coordinator

Mrs. Elna Harris, Social Media Coordinator

Mrs. Diane Blackwell, Administrative Secretary

Mr. Tony Blackwell, Fundraising and Merchandise Coordinator

SWEDEN - WED-FÖRBUNDET (WED-ALLIANCE)



Board. The board of WED-Förbundet (WED-Alliance) consists of five active members and three stand ins – five women and three males. All members have WED and are working in the organization for free. No salaries are paid. Only the costs for travel, accommodation and other expenses in connection with WED-activities are reimbursed. The board had five meetings – inclusive the Annual Meeting –, all physical meetings, during 2017. The chairlady elected in 2016 left her position abruptly in October 2017 due to burn-out symptoms. It had negative influence on all fields except the financial as I do them as a dictator. In most other activities it became stop as nobody knew so we must start from zero again in 2018.

Annual Meeting. The geographical place for the annual meeting moved around in Sweden so that all members at a specific time easily could come to an annual meeting. In March 2017 the meeting took place in Linköping 200 km south west of Sweden. In the future we will stay in Stockholm as it is optimal from all views.

“A life with Restless legs and bad sleep” come 2016 on the market. The book was written by Sten Sevborn. Angelika Alsfasser is a co-writer and Jan Ulfberg is a warrant for the medical issues. WED/RLS is presented on 230 pages. The price is 250 SEK (round 25 €). Members got a rebate with 100 SEK (round 11 €). The book was sold out (1,000 issues) during December 2017.

New WED/RLS book. Instead of just printing more issues Sten decided to re-wright the book. The name will still be “Alife with restless legs and bad sleep”. It will contain 265 pages and discuss everything of importance for WED/RLS. Everything which was in the first issue is still included. All chapters are up-dated. A few chapters are new. The price will probably be 250 SEK (27 €) and a rebate of 100 (11€) for member. Could also be used as a textbook for doctors. Will be printed in March 2018.

New WED/RLS-brochure – 20 pages. We created 2015 a brochure which is present in a stand in most primary care centers. During 2017 we have developed the brochure according to the newest level of knowledge. We have contract with Doctorn.com. They have a magazine coming four times a year. There we have an ad. The magazine named Doctorn.com is free in combination with our brochure in the waiting rooms. The total yearly cost is 15,000 €. The cost for the brochures are extra.

New WED/RLS-films were created.

Vi Nattvandrare (We Nightwalkers). The magazine for WED-Förbundet.comes four times a year. All fully-paid members together with 600 doctors, pharmacies and libraries get the magazine which has 24 pages and a lot of important information.

“A doctor life in the shadow of two world wars” is a book written by Professor Karl-Axel Ekbohm. The script was found by his three sons. WED-Förbundet made the dream true and sponsored the printing cost of the book, which contains 310 pages. It came on the market mid-2017.

Informational meetings. During 2017 we had only 5 informational meetings where we inform patients and other about WED/RLS. We arrange suitable localities, put ads in the newspapers and inform about WED/RLS. Our chair-lady was the only one who had access to needed material. It worked well in the beginning but stopped completely as she left. Shows the importance of not having just one person to do all or certain things. We sell memberships and books. In total we had 1,600 guests and got directly 220 new members and sold 300 books. Normally we have 30 info-meetings per year.

WED/RLS – Awareness Day. The Awareness Day is held on the birthday of Karl-Axel Ekbohm. We had this activity in only two places with specialists as presenters. Stockholm – Doctor Kurt Hedlund, Gothenburg – Sten Sevborn. In total we had round 250 guests and got 20 new members.

EURLSSG. Sten Sevborn together with Assistant Professor Jan Ulfberg participated in the annual meeting of EURLSSG in Munich in December 2017. Round 40 WED/RLS-researchers and/or clinicians from Europe and USA participated.

WASM and WSF had on 6th to 12th of October 2017 a congress in Prague, the Czech Republic. There was a lot of activities round WED/RLS. Over 2.100 -researchers and/or clinicians from all over the world took part. Sten Sevborn took, as the only delegate from Sweden, part in this very interesting days.

Sponsorships. There have been contacts with pharmaceutical companies for economical support. None of the companies had any possibility to support our activities. WED-Förbundet get since some years money from the health-authorities as a proof that we work in the right direction.

Vi Nattvandrare (We Nightwalkers) is the name of the Swedish magazine from WED-Förbundet. All members and a lot of doctors get four times annually Vi Nattvandrare. It contains 24 pages and is printed in four colors in DIN-A4 size.

Membership development. January 1st, 2017, we had 1,380 members. On December 31st, 2017 we had 1,386 members. We got 130 new members but lost 120.

Patient-doctor format. Sten have created an electronic format to collect all relevant patient-data in a double-sided DIN-A4 format.

Medical Product Agency re-started an activity with 16 selected patient advocacy groups which had to qualify to be allowed to take part. WED-Förbundet was accepted for participation. The activity is named Consumer Counsel. I, Sten, attended the meeting in March 2017. One of the topics was generic prescription. I have worked a lot with this topic and presented my view in the meeting. It was directly against what the lecturer presented. I was more or less told to be quit. I tried to get a separate meeting with the presenter. She had no interest and just left me. She know that I am right but can not accept that the ideas the authorities have are stupid. The second meeting I missed as I was in Prague for WASM. I will attend the next meeting if I will be invited.

THE NETHERLANDS – STICHTING RESTLESS LEGS



The Dutch RLS patient group, in its 18th year, now has approx. 1700 members, the group is flourishing and active. The Board consists of five people, each one of them active in different aspects of the work.

INFORMATION MEETINGS In 2017 four information meetings were held in different parts of the country. The program consisted of a lecture by one of the RLS specialist neurologists in our country, followed by Questions and Answers. Even after 18 years these meetings attract between 200 and 300 people each time. And the majority of the people still do not know that RLS is a serious disease. So the work is not yet done.

BROCHURES We have 8 different brochures:

- RLS - General information,
- RLS and pregnancy,
- RLS and depression,
- RLS and surgery,
- RLS in the elderly,
- Sleep hygiene,
- RLS in children,
- RLS and your partner.

All of these are available free of charge and are often requested; the one for surgery definitely is the one we send out the most.

NEWSLETTER Our printed Newsletter “De Nachtwacht”(The Nightwatch) is produced four times a year and is one of the things highly appreciated by our membership. Each issue has 12-14 pages and contains the latest news on RLS research as well as patient stories.

WEBSITE, TELEPHONE SERVICE We have a very active webmailservice, mails are answered daily by one of our members who has a very high degree of knowledge on RLS. We also have daily telephone service, manned by different volunteers every day. Our website is visited frequently and kept updated on a regular basis.

SCIENTIFIC ADVISORY BOARD The board consists of 10 specialist neurologists, one pharmacologist, and one geriatrician. We have put emphasis on bringing in the younger RLS specialists.

BOOK The book entitled “Living with RLS “ sold out in 2014 and a reprinted and updated edition was published in 2017.

NATIONAL COLLABORATION Our team works closely with the working party on movement disorders in The Netherlands as well as with the Dutch Brain Council and the Dutch Society for Sleep Medicine

INTERNATIONAL COLLABORATION Through our representation within EARLS as well as within EFNA, EMA and EBC, the knowledge gained from international groups is beneficial to the work we do and provides new and refreshing insights.

PUBLICITY/MEDIA We have advertised in local and regional media several times, each time resulting in greater visibility of RLS. On the occasion of International RLS day, a media campaign was done, resulting in one radio interview and one article in a national newspaper.

HEALTH INSURANCE We have found out that there is a shocking lack of knowledge among the managers of health insurance companies. In newspaper and television interviews some of them called RLS a “hype”, or even dared state that RLS is a disease “for which an operation is not necessary”. We have made efforts to enter into a discussion with these groups, so far with zero result.

FAMILY DOCTORS The Dutch General Practitioners’ Association issues so-called “Standards” for treatment, which are the guidelines for family doctors; these are also available for patients on the Association’s website. We have worked with the Association on renewing the Standard on Sleep Disorders, section on RLS.



OUR MISSION:

- Increase awareness of WED/RLS and work towards a better quality of life for people with WED/RLS.
- Establish strong partnerships with relevant stakeholders in the scientific, clinical, political and corporate world to help us and our members to reach our goals

OUR AIMS:

- To promote rapid and early diagnosis and better access to appropriate treatment
- To eliminate prejudice and stigma associated with WED/RLS
- Increase priority given by policy makers and decision makers to WED/RLS

EARLS fulfills its aims by working through

- Collaboration with relevant health professionals
- Collaboration with relevant scientific organizations
- Collaboration with relevant corporate partners
- Campaigning at European level
- Assisting in the development of national patient support organisations
- Whichever other activities the EARLS Board deems appropriate.

EARLS: Key action points 2018

- Through its position on the Board of the European Brain Council, EARLS endeavors to be the patient voice for WED/RLS at European level and to be actively involved in political advocacy at EU level.
- EARLS will in the coming years need to increase its communication, both internally and externally.
- The economic crisis and the competition for funding are a threat to EARLS's ability to function properly. Funding therefore must become an EARLS priority.
- The European Brain Council Project "Value of Treatment" is expected to increase awareness of RLS. By continuing to ask for attention of this important project we will ensure the patient voice is heard.
- EARLS will strive to further expand its current membership in the coming years
- EARLS will once again endeavor to develop an action plan for World RLS Day 2018 in collaboration with all national European groups as well as with the contacts in the USA and Canada.