



# Annual Report 2019

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# Introduction

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EARLS is now nine years old and we can proudly say that we have become an established partner within the world of patient advocacy in Europe as well as within the scientific groups working on RLS. Our key role remains to be a platform for our member groups, as well as collaborate with research groups, and this Annual report once again is the vehicle through which we can promote our work.

EARLS is increasingly active in the European arena as important decisions for neurological illnesses are being taken. EARLS brings together national patient groups working for Restless Legs Syndrome. Our mission is to provide maximum opportunities for people living with restless legs and to work toward relieving the immense burden on patients and their families, and society in general. We need to increase our capacity so that we can fulfill our role as patient representatives effectively. This requires a huge level of commitment and dedication from all of those who give their talent and expertise on a voluntary basis.

Resources are scarce and we are grateful to the support we have been given in the past, and we hope we may count on that again in the years to come.

The EARLS Board is determined to meet the challenge of representing our members at high level. Since our launch in 2010 we are acknowledged as a respected partner and responsible advocate for RLS. The role of patient organisations is increasingly moving towards centralised groups; therefore, we need to combine efforts more and more. I am confident that with the team that we have now, there will yet again be greater visibility and thus a chance of more attention for RLS patients throughout Europe.

I look forward to working with you once again in making RLS better known in the years to come,

Daragh Bogan, President

## Meetings EARLS executive board 2019

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- February 2019: General Assembly Meeting, Brussels
- March, June, September 2019: Various general and brainstorming meetings executive board
- June 2019, presence during meeting European Academy of Neurology. Oslo
- December 2019: Brainstorming members executive board, Munich
- Throughout the year, many telephone calls on the topics under discussion/consideration with various board Members

## Possible New Members

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Meetings have again taken place with the following RLS advocacy groups, whereby the dominant message has been that we need to combine forces in order to become a strong voice for WED/RLS: Existing Groups

German group – We were very pleased to welcome Mrs Katharina Glanz of the German RLS Patient group as an observer to this 2019 meeting

## **New Groups, contacts maintained/renewed**

Poland – Mrs Magdalena Sklarek. Contact renewed, no real progress. New contact is Dr Marius Szieminski from Gdansk.

Rumania – Mrs Viorica Cursaru, follow up meeting during 2017, no real progress

Portugal – Mrs Ana da Gama, no real progress

Denmark – Prof. Poul Jennum, contact re-established, no progress at this stage

Greece – Dr Giorgios K Sakkas, on going discussions

## **Japan**

We have been approached by the Japanese RLS Patient Organization, requesting the rights to translate the EARLS Patient Survey into the Japanese Language. Permission has been granted and the study has been translated into Japanese.

## **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 within Europe.

## Representation

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In 2019 EARLS was represented at various events and conferences. Below are some examples:

- June 2019, European Academy of Neurology Congress.Oslo. Patient Awareness Corner. Many contacts made, much information on RLS distributed to scientific community. ~8,000 neurologists attending



- February, June, September and December 2019, European Medicines Agency. EARLS participates as Member of the Patients and Consumers Working Party
- Throughout the year, meetings at the European Brain Council.

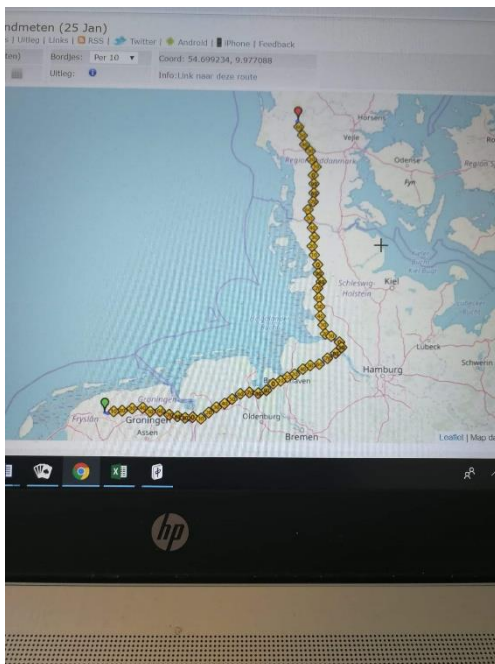
- December 2019, Munich: EARLS is an active member of European RLS Study Group. Presentation of VoT outcome
- EARLS is an active member of the Education Committee of the European Academy of Neurology
- EARLS participates in the Scientific Panel Meetings on Sleep Disorders, Palliative Care as well as on Movement Disorders at European Academy of Neurology Conferences.
- Through its EFNA membership EARLS is also represented at organisations such as the European Brain Council, European Alliance for Access to Safe Medicines, European Medicines Agency,

### **Lucy'sWalk**

During the summer EARLS helped organize and supported a major awareness campaign, in collaboration with the Dutch and German RLS associations.



During the month of September, Dutch RLS patient Lucy Hoekstra walked 486 kilometers, from her home town in Friesland, The Netherlands, to the small town of Esbjerg in Denmark, where Lucy's sister lives. She completed the walk in 28 days, and during her walk she created much awareness for RLS in the countries she passed through (Netherlands, Germany, Denmark),





but also, through the EARLS members and website, where we made sure there were daily updates of her walk, as it turned out worldwide. This led to articles in many newspapers, to TV and radio coverage, and an article in the US RLS newsmagazine.

Concluding, this was a major awareness campaign for RLS.



## Finances 2019

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Balance as per 31-12-2019 € 8,433.25

Details of the financial report will be presented during our General Assembly meeting. It is increasingly difficult to obtain funding.

### External appointments

As of April 219, Joke Jaarsma has been elected President of the European Federation of Neurological Associations (EFNA).



## 2019 and beyond

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### **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 2019-2020

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- Through its position on the Board of the EFNA and EBS, 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