



Annual Report 2018

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Date 2019-04-06

Introduction

The European Alliance for Restless Legs Syndrome (EARLS) remains a respected partner at both a patient-advocacy level and in scientific groups specialising in RLS and we continue to provide a platform for our member groups across Europe.

At a time of change across Europe, the importance of a unified patient voice is becoming more apparent. EARLS remains an independent organisation - which it has always been - dedicated to helping RLS patients across all of Europe and we continue to reach out to new and existing RLS groups to share knowledge, learning, experience and to improve patient pathways.

Our most significant piece of work this year has been the launch of the EARLS 2018/19 Patient Survey on 23rd September 2018, International RLS Day. To date, we have received 3,341 responses and we hope to achieve our target of 5,000 responses by 23rd September 2019. Participating countries to date are Austria, Germany, Finland, France, Ireland, Norway, Sweden, The Netherlands, and the UK. We have had expressions of interest from across the world regarding our survey, both from countries interested in taking part and from individuals interested in our findings. Interim findings will be provided at the 2019 EARLS General Assembly while final findings will be launched on International RLS Day 2019.

I had the honour of presenting interim findings of our survey to the European Restless Legs Study Group (EURLSSG) at their annual conference in December 2018 and am delighted that we have been invited to present our final findings to their 2019 conference attendees.

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 during 2019 and also in the years to come.



Daragh Bogan, President



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

Delivering Our Aims

EARLS continues to fulfil 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.

Ongoing Action Points

- Through its position on the Board of the European Brain Council, EARLS endeavours to be the unified patient voice for WED/RLS at a European level and be actively involved in political advocacy at EU level.
- Funding continues to pose a threat, at a time when increasing numbers of RLS patients are accessing our services. Funding therefore remains a priority for our organisation.
- EARLS will strive to further expand its current membership in the coming years
- EARLS has developed an action plan for International RLS Day and will once again collaborate with all national European groups as well as with the contacts in the USA and Canada.

Meetings EARLS Executive Board 2018

February 2018: General Assembly Meeting, Brussels



L-R: Katharina Glanz (Guest), Germany; Erling Gulbrandsen, Norway; Waltraud Duven, Austria; Veli-Matti Riitamaa, Finland; Milja Saesvaara, Finland; Daragh Bogan, United Kingdom; Mirose Gard, France.
Not in photograph: Sten Sevborn, Sweden; Peter Reijngoud, The Netherlands; Robert Parisot, France

Membership

We continue to engage with RLS advocacy groups across Europe and meet with them to communicate opportunities to collaborate and 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 2019 meeting.

Spain – We are also very pleased to welcome Sagrario Casino of the Spanish RLS group (AESPI). Spain has been a key partner in the delivery of our work, and we look forward to continuing this important work in the future.

New Groups

Ireland – We have had many enquiries from people living in Ireland who were looking for help and support with their RLS. We are therefore particularly pleased to welcome Gillian McKenna to our 2019 meeting, who is exploring opportunities to start an RLS support group in Ireland.

Activities & Representation

During 2018, EARLS progressed its outreach and stakeholder work through various channels, events and conferences. Below are some examples:

March 2018

- Administration: discussions with the notary. Significant administrative work underway which we anticipate completing by end Q1 2019.
- New administrative Belgian address arranged for these purposes.
- Presentation of RLS VOT case in European Parliament in Strasbourg
- Participation in campaign for young neurology advocates

June 2018

- Attendance at European Academy of Neurology in Lisbon.
- Participation in preparations for meeting in Oslo 2019 (Erling and Joke)
- RLS presented in scientific theatre at EAN
- Presentations of RLS case in a special session arranged for the Value of Treatment Study by Joke Jaarsma and Prof Wolfgang Oertel.
- Participation in Scientific Panel on Sleep
- Attendance at EFPIA (European Federation of the Pharmaceutical Industries). Many contacts made.

July 2018

- Attendance FES meeting, Berlin
- Meeting with UCB, Brussels

September 2018

- EARLS presentation at RLS-UK GA in London
- International RLS Day: Launch of 2018-19 EARLS Patient Survey

November 2018

- Awards Ceremony EFNA: Prizes for best young scientist advocate (Sakkas) and lifetime achievement award (Oertel), both RLS researchers, at gala dinner were presented these awards. Nominations by EARLS.

December 2018

- EARLS was sponsor of first ever EURLSSG congress day for GP's
- Attendance at annual EURLSSG congress

January 2019

- Meeting in the European Parliament together with EAN executive where RLS case was once again discussed.
- New sponsorship agreement made with VIFOR Pharma.
- Presentation of RLS case to audience of 600+ including many Portuguese parliamentarians in Lisbon.

Finances 2018

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

Transfer from 2018	€ 11,190.13
Total new Income, 2018	€ 300
Total Expenses, 2018	€ 3055.90 (2,500 to EURLSSG)
Transfer to 2019	€ 8,434.23

Details of the financial report will be presented during our General Assembly meeting.

Our total remaining working capital, at the time of writing, is therefore €8,434.23.

External Appointments

Joke Jaarsma has been elected and will serve a two-year term on the Board of the European Federation of Neurological Associations, from General Assembly 2019 to General Assembly 2021.



Reports from EARLS Members

Finland - Levottomat Jalat – Restless Legs ry



Levottomat Jalat – Restless Legs ry has arranged with its umbrella organization, the *Finnish Sleep Union (Uniliitto)* at various lectures, information desk services, peer groups, shared free magazines and brochures and posted this material also to health centers and hospitals. In these events the association has worked for better knowledge and treatment of RLS/WED.

Lectures, Events and Information Desks

26.3.-1.4: “Alertness Week” (Uniliitto’s theme week) info desks and lectures mainly at Kamppi’s activity center, 250 participants

18.4: Patients rights forum day in Helsinki University Hospital. RLS/WED info desk, 80 visitors

2.5, 14.5. 16.5. and 9.11: Lectures including RLS/WED, participants 132 participants

27.7: “Seven Sleepers Day” event at Helsinki, Kamppi market square, RLS/WED info desk. 100 visitors.

RLS/WED awareness day, 20.9: Helsinki university “tower” Hospital, 30 visitors.

3.9: “Think tank – evening” about RLS/WED considering new methods for promoting information about RLS/WED and our possibilities to get some new active organization members, 8 participants.

29-30.10: RLS/WED was also included in our sleep medicine training days for doctors and other healthcare professionals, 180 participants.

Peer Support Groups

Restless Legs Association organized patient's peer support groups in Helsinki, Vantaa and Tampere. Peer support groups are trying to improve the RLS/WED syndrome patients and their close ones' quality of life. Peer support groups are preventing social exclusion due to sleep disorders. The groups discussed and shared self-treatment advices.

Helsinki1: 7 meetings, 31 attendances; Helsinki2: 9 meetings, 48 attendances; Tampere: 10 meetings, 50 attendances; Vantaa: 8 meetings, 40 attendances

Patient Counselling

Our office staff and volunteers gave telephone counseling and personal patient counseling at our office, opening hours Monday to Friday 10.00 - 16.00.

Information

Levottomat Jalat -RLS website locates in Uniliitto’s websites at www.uniliitto.fi.

EARLS survey was included on our web-pages after it was published and translated.

Uniliitto’s and its member organizations Uniutiset-magazine was published 4 times in 2018 and was sent to all the members of associations belonging to Finnish Sleep Union.

Office

Levottomat Jalat – Restless Legs’ office is located in Uniliitto association's office at Sitatori 3, 00420 Helsinki.

France – Association France Ekbohm Jambes Sans Repos



AFE General Assembly, June 2018, Strasbourg

Interesting intervention of Dr Petiau (Neurologist in Strasbourg) who presented a piece on the RLS - which followed a “Round the Table” under the subject “understanding the pathology for a better management of the treatment”. What emerged from this is that the treatment with dopaminergic agonists is tending to be suppressed due to the importance of undesirable effects. To minimize this risk, the lightest dose possible must be given and in case of side effects and complication such as behaviour disorder (shopping, game, sexual and alimentary) the solution is to make a definitive weaning of the agonists dopaminergic. The weaning must be followed by a regular medical monitoring. Two patients who completely abandoned the dopamine agonists talked about their experience – few days difficult but conclusive and regenerating.

AFE Treasurer

Since 2016, France-Ekbohm was looking for a Treasurer. Until today, the job was held by the President (Robert Parisot) and this situation couldn't continue. After few discussions, Ms. Mirose Gard Contet agreed to take the job of Treasurer.

Communication

- We have put a special emphasis on the development of our website, Facebook page and Twitter.
- May 2018: TV show "Allo Doctor" was dedicated to our pathology.
- A Few publications in newspapers, "Femme Actuelle Senior" "Alternative Health" with an interview of our president.
- Our presence at the Sleep Congress in November 2018 in Lille. During this congress we took advantage to meet the specialist of RLS and therefore we can expand the list of RLS specialists available for our members.

There is an increasingly important interest on the part of our members looking for natural treatments (cannabis therapy, acupuncture, cryotherapy, meditation etc....)

Ronald Mary, Journalist and writer suffering from RLS wrote a practical Guide to understanding and accompanying RLS by complementary medicines and natural methods. He asked for AFE's opinion before publishing it. Few members of the Board of Directors, including Dr. Velour found it very complete or well explained. Prof. Yves Douvillier's, RLS specialist and member of our Scientific Board, prefacing the guide. As soon as it will be done, the book will be published.

In 2019, we are going to do 2 bids for a total amount of 80K€
Numbers of members remains constant = 2'200

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 2018 the group had 417 paying members.

General Assembly, 2018 – New Board

Our General Assembly was held in Oslo in April 2018 and the following board was elected:

Leader: Berit Caroline Egseth

Board members: Helen Olsen (deputy head); Sunniva Jakhelln

Vara members: Dagrun Fikkan Slørdal; Tone Naas

Election committee: Erling E. Gulbrandsen

In September 2018, Tone Naas retired from her position as vara for the board.

Membership & Board Activity

At the end of 2017, the FRB group/organization had 427 paying members. Among these, 362 have retained their membership into 2018. In addition, 55 new members have been recruited. Hence, at the end of 2018 the group had 417 paying members.

During 2018 there has been 5 ordinary board meetings with a total of 48 points on the agenda. In addition, there has been one working meeting engaged in establishing a new lay-out model for our magazine, *Maurtua*. A major initiative from the new board has been to reassure the level of economical control and planning in the group/organization. This work has resulted in a considerable strengthening of the financial base of the FRB.

Otherwise, the main activity of the board consists in information activities directed towards the public – as well as applying for financial support from various kinds of funding – both in the public health care system and from private foundations. Each paying member of the FRB brings a certain amount of financial support from the Norwegian health department. Apart from that, it seems to have become increasingly difficult to raise money from external sources in recent years.

Membership & Board Activity

The General Assembly (in spring 2018) was arranged together with the FRB group's annual National conference, as usual. In a survey that was conducted afterwards, members expressed varying opinions as to the program and the practical organization of the conference. The planning of the upcoming 2019 conference has been reworked accordingly.

International RLS Day

As always, International RLS day on 23 September was marked with distribution of information material on RLS to the public. Also, board members produced a new information video on RLS that was launched on 23 September and disseminated on social media, reaching thousands of viewers.

Communications

A new and updated information film on RLS will be produced and the planning of this project has been settled by the board. As yet, external funding has not been obtained but the work goes on.

The drifting of the local group of the FRB in Mid-Norway (Trøndelag) has been cancelled due to lack of resources.

FRB members receive our printed bulletin, *Maurtua* (*The Anthill*) which is issued two times a year, as well as other written information on RLS and on our different information activities. Paying members also have exclusive access to the group's patient forum on Social Media (our FRB group on Facebook), which currently has 93 members. Also, the FRB is drifting an open information page on Facebook which is accessible to the general public.

During 2018, after expressed wishes from a majority of members, the board decided that the printed bulletin, *Maurtua* is now again offered primarily as a magazine printed on paper. Hence, the magazine is distributed to all members by post. Also, a new design and lay-out has been settled. Berit Egseth has been editor-in-chief, with editorial support from board member, Sunniva Jakhelln and with professional technical assistance from Orgservice.

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, practical arranging of general assembly, and lay-out, design and printing of *Maurtua* and other written information material.

The Norwegian Section is member of the EARLS (European Alliance for Restless Legs Syndrome). Our representative there is former board member in FRB, Erling E. Guldbrandsen. As a representative of the patient group in EARLS, Guldbrandsen participated as an invited guest at the EAN Congress (European Academy of Neurology) in Lisbon on June 16–19.

Oslo, 25 March 2019

Berit Caroline Egseth (leader)
Helen Olsen (deputy leader)
Sunniva Jakhelln (board member)
(English version: Erling E. Guldbrandsen)

United Kingdom – RLS-UK



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.

Performance

- We have continued to grow and to raise awareness of RLS and have achieved and exceeded most of the objectives we defined for the past year.
- While our number of Facebook followers has increased by 50%, 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 website, launched in February 2017, has been visited almost 219,000 times (up 125% in the past year) and visitors have viewed almost half a million pages of content.
- Our new leaflets have been produced and sent to 3,000 medical centres across the UK.
- We have continued to explore new funding avenues and have seen a significant increase in membership numbers and donations, which in itself has bolstered our funding.

Structure & Governance

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. Monica Twamley, formerly our Membership Coordinator has departed from the group and this position has been filled by Tony Blackwell.

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 men. All members have WED and are working in the organization for free. No salaries are paid, only 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 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.

Printed media

“A life with Restless legs and bad sleep”: A book was written by Sten Sevborn in 2016. Angelika Alsfasser was a co-writer and Jan Ulfberg was 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. More recently, 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 in combination with our brochure in the waiting rooms. The total yearly cost is 15,000 €. The cost for the brochures is extra.

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.

Information Meetings

During 2017 we had only 5 informational meetings where we inform patients and other about WED/RLS. We arranged 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.

International RLS Day

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.

World Association on Sleep Medicine (WASM) and World Sleep Federation (WSF)

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 these very interesting days.

Sponsorship

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.

Membership

On 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 created an electronic format to collect all relevant patient-data in a double-sided DIN-A4 format.

Medical Product Agency

They 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 knows that I am right but cannot 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 was in its 19th year in 2018 and is preparing for 20-year celebrations. We have approximately 1700 members, the group is flourishing and active. The Board consists of five people, each active in different aspects of the work. In 2018 we saw a major revision of our website.

Information Meetings

In 2018 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 19 years these meetings attract circa 150 people each time. And the majority of the people still do not know that RLS is a serious disease. So there is work yet to be done.

Printed media

We have 8 brochures: RLS - General info; RLS & pregnancy; RLS & depression; RLS & surgery; RLS in the elderly; Sleep hygiene; RLS in children; RLS and your partner. All are available free of charge and often requested; RLS & Surgery is most often sent out. Brochures also available online.

We have advertised in local and regional media several times, each time resulting in greater visibility of RLS. On International RLS day, a media campaign was done, resulting in one radio interview and an article in a national newspaper. A popular weekly published a 10 page article on RLS.

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 webmail service, mail is 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 more frequently since its relaunch.

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.

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. The release of the Value of Treatment Study on RLS in 2017 has led to much awareness of RLS. In 2018 RLS was presented at many major meetings in Europe, and this continues in 2019.

Family Doctors

The Dutch General Practitioners’ Association issued so-called “Standards” for treatment, which are the guidelines for family doctors; 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.

Dutch Brain Council

The RLS group have put much effort in making the DBC more active. This is ongoing work. Collaboration with other main brain-related patient groups is ongoing.

Spain – Asociación Española
De Síndrome De Piernas Inquietas



ASOCIACIÓN ESPAÑOLA DE
SÍNDROME DE PIERNAS INQUIETAS

En primer lugar, como Presidenta de AESPI y en representación de todos los afectados de SPI en España, quiero agradecer a la EARLS la invitación para que estemos aquí y podamos compartir y escuchar nuevas ideas y poner en común nuestras experiencias e inquietudes.

Por diversas circunstancias coyunturales de renovación y dimisión de Juntas anteriores, la asociación funcionó con una Junta Gestora siendo nombrada en abril del 2017 Presidenta de ella. Durante ese año se fue conjuntando una nueva Junta que fue ratificada por la asamblea de socios el 22 de septiembre. En este período se han realizado diversas actividades, todas ellas con el propósito de mejorar y crecer como asociación, siempre pensando en el bienestar del enfermo de SPI.

Se ha puesto en funcionamiento una nueva página web, más ágil y sencilla para todos los socios y los usuarios que deseen entrar en ella.

Ésta, al igual que la Guía de Información sobre la enfermedad de SPI, que también se ha realizado y proporcionado a todos los socios, se puede ver nuestra página web.

Un nuevo canal de YouTube, en el que retransmitimos en directo los actos y conferencias, permite mantener informados a quienes no pueden desplazarse a los diferentes eventos realizados y en el que se ha colgado un pequeño vídeo promocional de AESPI que resalta nuestro principal lema: "Que no te sientas solo".

Siendo conscientes de la importancia que en la actualidad tienen las redes sociales, mantenemos actualizados tanto Facebook como Twitter proporcionando información contante a todos aquellos que quieran acceder, siendo también nuestra conexión con países de Sudamérica que, por desgracia, no tienen los medios de los que nosotros disponemos y tratamos de dar apoyo e información a través de mensajería.

Todas estas iniciativas han sido primeramente aprobadas por los asociados en nuestra Asamblea anual.

A lo largo del año se ha mantenido contacto con diversas entidades y se han incorporado como colaboradores a dos especialistas médicos, además de enfermeros, fisioterapeutas y nutricionista.

Además de estos profesionales, aprovechando que tenemos un asociado que es psicólogo, se ha incorporado a la Junta como tal y se le han dado funciones para poder atender por teléfono o vía página web a los socios que lo soliciten a través de un foro activo que ofrece ayuda e información a visitantes y asociados.

Este mismo socio actualmente es el encargado de las relaciones entre AESPI y la ONG "Educación Sin Fronteras" la cual, gracias al gran trabajo de formación de equipos de médicos y expertos en la sanidad, realizará unos cursos on-line para formar e informar tanto a pacientes como a profesionales de la sanidad.

El 2018 se realizó una conferencia a cargo de la Delegada de la Comunidad Andaluza, Dña. Purificación Titos. En Sevilla pudimos disfrutar de una interesante ponencia para todos los públicos ofrecida por un doctor especialista.

Como Presidenta, participé en varios medios audiovisuales a lo largo del año (radio y televisión) ofreciendo información de nuestra Asociación.

El año finalizó con una Asamblea anual de Asociados y la celebración del día Mundial de SPI en Madrid con un programa muy elaborado y la participación de expertos colaboradores que, como en ocasiones anteriores, ofrecieron a los asistentes información actualizada sobre los avances de nuestra enfermedad.

El 2019 comienza con una Conferencia de la Delegada en la Comunidad Valenciana y Vicepresidenta de la Asociación, Ana Jiménez, en Torreveja, Alicante, dando a conocer la enfermedad, tanto a miembros de la profesión sanitaria, como a todos los ciudadanos, obteniendo una importante difusión en los medios.

Nuestros proyectos futuros son:

- Realizar una revista anual para todos los asociados y que a su vez se colgará en la página web.
- Continuar con nuestras conferencias. Hay previstas tres más en distintas comunidades que servirán para dar a conocer más la Asociación.
- Celebrar como cada año el Día Mundial del SPI y la Asamblea anual de Socios.

En el mes de marzo, y celebrando el Día Mundial de las enfermedades raras, AESPI ha sido invitada a una semana cultural en la que participarán diferentes asociaciones. Una representación de la nuestra acudirá, junto con un médico colaborador, ofreciendo una pequeña exposición de nuestra enfermedad y de la asociación.

Además de todo esto, este año nos hemos propuesto que AESPI sea clasificada como "Asociación de interés social". Esto conlleva mucho trabajo y esfuerzo. Para ello hemos formado un comité dirigido por un socio que se ofreció a trabajar en ello dados sus conocimientos en leyes. Este logro sería muy favorable ya que nos facilitaría la vía para conseguir ayudas económicas y un reconocimiento público y sanitario.

Por último, asistiremos a dos eventos que se realizarán en el País Vasco y a los que estamos invitados.

Actualmente la Junta está formada por un equipo en conexión constante, con muchas ganas de trabajar y proponiendo ideas para un mejor funcionamiento de AESPI.

Como Presidenta de la Asociación, me siento muy agradecida por el reconocimiento de nuestro trabajo.

Nuestro objetivo es avanzar y conseguir avances, siempre pensando en el enfermo de SPI.

Sagrario Casino

Teruel a 03 de marzo de 2019

