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DEBRA Worldwide

Argentina
Australia
Austria
Belgium
Bosnia and Herzegovina
Brazil
Bulgaria
Canada
Chile
China
Colombia
Costa Rica
Croatia
Czech Republic
Finland
France
Germany

Hungary
India
Iran
Ireland
Italy
Japan
Libya
Malaysia
Mexico
Moldova
Netherlands
New Zealand
Norway
Poland
Portugal
Romania
Russia
Serbia

Singapore
Slovakia
Slovenia
South Korea
Spain
Sri Lanka
Sweden
Switzerland
Taiwan
Tunisia
Turkey
Ukraine
UK
USA
Message from the President

Dear DEBRA Members & Supporters,

It’s been a busy year at DEBRA International as we have, and still are, going through a lot of changes in our structure; changes which will strengthen the organisation for many years to come. We now have a Business Manager, Olivia Mullins, who has been in place for over a year and has settled in brilliantly. We are making changes in our governance structure that will help us further professionalise DEBRA International and we hope and believe this transitional period will help us to better support our member groups and, ultimately, improve the lives of all those living with EB and their families now and in the future.

In this 2017 report, we cover just a small part of what has been undertaken by DEBRA International. You can read in more detail about these projects throughout this report and I’m sure you’ll agree we are embarking on some very exciting work that we hope will make a real difference in the fight against all types and severities of EB. 2017 has seen the launch of new research grant rounds including calls for projects on wound healing in EB, and on concepts/technologies novel to EB. We look forward to hearing updates on these projects in 2018. The Psychosocial Clinical Practice Guideline (CPG) is well underway and developing nicely, the hugely important Management of Anaemia CPG is set to start soon, plus work is commencing to translate these and other CPGs into different languages, making them truly international.

DEBRA International now has 48 national member groups and our membership continues to grow with more countries from all over the world joining our ever-expanding network. We also continue to have a strong presence in various international rare disease associations, including the ePAGs (European Patient Advocacy Groups), which are part of the ERN (European Reference Network), RDI (Rare Disease International), and the IADPO (International Alliance of Dermatology Patient Organisations).

There is still much work to do though and it’s hugely important that we continue to build partnerships and keep communication open with all DEBRA and other EB/dermatology groups as well as our partners in industry. It’s only by continuing to work together, as we have done, that we can help people and their families with EB as much as possible. As someone who lives with EB, I feel that viable treatments are now a reality on the horizon instead of just a dream - the road is still long but the end is now in sight.

So this just leaves me to say, on behalf of all members of the DEBRA International Executive Committee, thank you to all the people who have contributed to our work in the last year. This includes our Business Manager - Olivia Mullins, Head of Research - Clare Robinson, EBWB (EB Without Borders) Co-ordinator - Leo Prujean, CPG Co-ordinator - Kathy Mayre-Chilton, and of course the many volunteers including those in our EBWB team and CPG panels who dedicate their time to our cause. I would like to say a very special thank you to our CEO - Michael Fitzpatrick, who is standing down from his role after many years of service; Without Michael’s dedication and hard work we wouldn’t be in the strong position we are now moving forward. I’d also like to say a huge thank you to DEBRA International Executive member, Avril Kennan, who has been instrumental in creating the Clinical Practice Guideline project and has played an important role in the EB Patient Registry Project. She will be sorely missed by everyone she worked with at DEBRA but I am sure you will join me in wishing her the best of luck for the future.

The future is bright for DEBRA International but we are always looking to improve and help people as much as we can to live a better life with EB.

Best wishes to all,

Mike Jaega
President
DEBRA International

Our Achievements

Our recent achievements include:

- Greater involvement of people living with EB in research and the Clinical Practice Guidelines through the DEBRA International Research Involvement Network
- Newly-acquired Basecamp is a tool for all members to use and centralise resources and information
- Recognition in the international rare disease world as a major player with significant influence in international patient associations and policy development
- New DEBRA groups recently formed in India, Turkey, Tunisia, Algeria, Albania, and Sri Lanka through the mentoring of EB Without Borders
- CPG network has grown to over 250 people with 7 new areas under development and more expected in the future

Business Manager Report

It’s hard to believe that it’s already been 1 year since I first stepped into the DEBRA world and I would like to say a huge thank you to everyone for making me feel so welcome. It’s been a packed year full of new experiences; I’m proud of what we’ve been able to achieve over the past year and look forward to seeing what the next will bring.

We have big plans for 2018 so watch this space! Further professionalising the governance structure of DEBRA International will continue to be a priority in 2018 with the development of new committees and a 3-year strategic plan. Additional proposals include breathing new life into DEBRA International’s image with the launch of a brand new website, further developing the EB Patient Registry, supporting new DEBRA groups in their creation, and building on existing and new partnerships with other organisations.

Our work is not possible without the great in-kind support we receive from our member groups and further thanks are extended to those who provided additional contributions this year. At DEBRA International, we feel that it’s important to be able to give something back and 2017 saw the acquisition of Basecamp, a web-based project management and collaboration tool, which is free to all our member groups to use. Finding other ways to help reward our member groups will form part of our priorities list for 2018. Our work is also very much aided by our external partners and our thanks go out to all of them for their continued support to our cause.

Olivia Mullins
Business Manager
DEBRA International
The Role of the Executive Committee

The Executive Committee currently has representatives from 12 national DEBRAs. Members, elected on a rotational basis every 3 years, are responsible for the governance of the organisation, sharing accountability for its work, setting the strategic direction, and leading its activities. The Committee has monthly conference calls and meets annually at the DEBRA International conference where 1 day is devoted to setting out the aims for the coming year.

DEBRA International Work Streams

These are the key priorities for DEBRA International over the next 12 months. We encourage anyone who may be interested in becoming involved in these work streams to please get in touch.

Research

Despite poor wound-healing being a priority unmet clinical need, few proposals for such clinical research are received. To focus attention, we held an ‘expert round-table meeting with both EB research clinicians and non-EB wound-healing researchers, in the expectation of eliciting new research concepts, and interest in EB among senior researchers with expertise from other disciplines.

The review of current knowledge and challenges in EB wound healing identified opportunities – a summary was published in the British Journal Dermatology; and the full report is at http://bit.ly/DEBRAWoundHealingMeetingReport.

A call for research proposals based on identified priorities was held in 2017 and, of the 18 full proposals received, 3 will be funded by DEBRA UK, 2 from research groups new to EB.

The expert round-table approach will tackle a further priority area in 2018: the chronic inflammation of non-healing wounds in severe EB that leads the fibrotic contractures and an increased cancer risk. A subsequent call for research proposals in ‘inflammation, fibrosis and cancer’ is planned for the latter half of 2018.

A call for research proposals across all four of DEBRA’s priority areas was also held, and DEBRA Austria anticipates funding 4 of the 21 proposals – in RDEB gene therapy, novel EBS drugs, new clinical approaches addressing causes of failure to thrive in JEB and RDEB, and a grant extension characterizing novel EBS gene mutations.

DEBRA Austria hosted the ‘EB2017’ research conference in September, for the first time in conjunction with the annual ‘EB-CLINET’ meeting. The decision to do this reflected the rapid clinical translation of research into symptom-relief treatments and disease-modifying ‘curative’ treatments. Enabling clinician – research dialogue on emerging therapies and planned clinical trials allows feedback on clinical and patient priorities. Representatives from biopharma industry were numerous, and welcome as future partners in therapy development and delivery. Notable also were new concepts for treatment based on deeper understanding of EB biology.

Many younger researchers were given an opportunity to present their work at EB2017, in line with DEBRA’s strategic priority of developing the next generation of researchers. The joint conference, with more than 300 delegates, was dedicated to the memory of Professor Robin Eady, in recognition of his enthusiastic support over many decades for researchers, clinicians and people with EB, young and old alike. DEBRA International intends to create travel bursaries in Robin’s name for postdoctoral researchers and young clinicians keen to develop careers in EB.
A key theme of EB2017 was to consider lessons from a decade of clinical translation in guiding what we do next, as well as to prioritise future DEBRA research funding. Although the majority of DEBRA International research funding to date has come from DEBRA Austria and DEBRA UK, it is encouraging that other DEBRAs now wish to support research moving forward. Equally valuable is that DEBRAs that develop their own national research support schemes are adopting the funding principles developed by DEBRA International: doing so facilitates future collaborations and interactions with other charities and funding partners.

Recent disappointing results from a couple of clinical trials highlight the importance of designing trials that recognise the characteristics and rarity of EB, as well as the needs of enrolled patients. DEBRA has engaged on a one-to-one basis with many companies, but a consortium approach is needed to address more effectively common pre-competitive issues now in development.

A theme for DEBRA International research support over the past year has emerged as ‘widening our dialogue with all stakeholders in developing and delivering EB treatments’. Plans for 2018 and beyond continue this approach.

Dr. Clare Robinson  
Head of Research  
DEBRA International

Research Involvement Network (RIN)

This year has seen the launch of the DEBRA International Research Involvement Network (RIN). Created for people who are interested in International Research Involvement Network (RIN). Created for people who are interested in

Clinical Practice Guidelines (CPGs)

One year on as Coordinator of the DEBRA International Clinical Practice Guidelines (CPGs), and the new Wound Care Guideline review has been published, the Nutrition: Constipation Guideline in its final stages, and 7 new CPGs are being developed internationally. It’s been a busy year where we have continued to develop individual guidelines for varied aspects of EB clinical care.

The Wound Care, Pain Management, Oral Healthcare, and Cancer Management guidelines are accessible online via the DEBRA International website for everyone living with EB around the world. 21 guidelines have been identified for development so far. We have a long way to go but we are very excited by the progress all the development guideline panels have made! I would like to thank the numerous volunteers involved in the CPGs for everything they have done for this incredible initiative to develop CPGs for EB to improve future care, and of course to our funding DEBRAs who help to make them a reality.

Dr. Avril Kennan has been instrumental in the development of the CPGs in supporting and increasing awareness of their importance and necessity. She left DEBRA in August 2017 for an exciting new opportunity. We would like to thank her for all her guidance with the CPGs and wish her all the best for the future.

Whether you are a clinical expert in EB, an EB nurse, someone living with EB, or someone caring for someone with EB, you are important to the development of the CPGs. If you would like to find out more about how the CPGs are developed, and how you can become actively involved, please visit www.debra-international.org/clinical-guidelines or do not hesitate to contact me.

Dr. Katty Mayre-Chilton  
CPG Coordinator  
DEBRA International

Have your say in EB research!

• Review grant proposals
• Join our CPG panels
• Take part in surveys
• Find out about current clinical trials

2017 Highlights

The CPG network has grown to over 250 people, many of whom have committed to being involved in the development of 1 or more guidelines as members, chair, leads and/or reviewers of the final drafts. 133 volunteers have been working on the 10 CPGs this year representing almost all continents. 25 (19%) of these people living with EB from 7 countries around the world are acting as full panel members.

The new Wound Care Guideline is yours online via the DEBRA International and EB-CLINET websites.

The CPGs under development this year have received funding from DEBRA Norway, DEBRA UK, DEBRA Austria, DEBRA USA, and DEBRA Canada, for which we are very grateful.

7 new areas under development include psychosocial, occupational therapy (OT), anaemia, podiatry, diagnosis and laboratory diagnostics, physiotherapy, and hand surgery and rehabilitation therapy.

Both the EB-CLINET and DEBRA International Congresses in 2017 are hosting CPG panel meetings.

New translation standards have been developed and DEBRA Spain will lead the translation of the new Wound Care Guideline into Spanish, for which we are very grateful.

Funding permitting, we hope to see further progress in the development of new guidelines sexuality and the women’s health and child birth and the review of the oral health care, over the coming years.
International EB Patient Registry Project

There have been some exciting developments since our last update on the International EB Patient Registry Project.

Work began on collating various datasets from EB registries around Europe. These datasets have been used to complete the first phase of a mapping exercise to identify a consensus dataset, which will be made freely available to any clinical centre wishing to develop or update an EB registry. Our thanks go out to those clinical centres who shared their datasets with us. In order to facilitate the central sharing of data, we are working to identify a core dataset from the larger consensus dataset, which would be mandatory for clinical centres to collect information on.

The consensus dataset has been incorporated into a demo EB registry, which can be viewed here: http://bit.ly/EBRegistryDemo. We encourage clinicians to log in, add fictitious patients with fake data, play around with it, and let us know your options in order to bring a co-ordinator on board. The appointment of a registry co-ordinator will be of benefit to driving the project forward. DEBRA International will lead on exploring funding outcomes of the meeting was the consensus that the consensus that the appointment of a registry co-ordinator will be of benefit to driving the project forward. DEBRA International will lead on exploring funding options in order to bring a co-ordinator on board.

We welcome interest from anyone who would like to find out more about the Registry Project, the Registry Co-ordinator role, and participating in the Governance Committee so please do not hesitate to get in touch.

Olivia Mullins

External Partnerships

Partnerships with other organisations with complementary objectives are an important part of DEBRA International’s strategy in the fields of advocacy, care, research, and fundraising.

National DEBRAs advocate on behalf of people with EB with their own national institutions whilst DEBRA International advocates on issues with a regional and international dimension. In a globalised world, many policy decisions made by international institutions affect people with EB, and DEBRA International is active in many of the most influential multinational organisations relevant to people with EB. In addition, many awareness raising actions benefit from a cross-border approach, such as EB Awareness Week.

Some areas of research that DEBRA International has funded are now at a stage where there is a realistic prospect of developing clinical treatments, and we are considering how best to translate the most promising research to the clinic. Partnership development with industry is crucial to enabling clinical trials and delivery of improved therapies to be planned. Whether individual companies are in a position of 'watch and wait', to collaborate, or to initiate their own EB R&D programmes, all wish to have some degree of contact with DEBRA International as a patient organisation and the associated clinical community, both for information and access to patients.

We invite organisations and industry alike to talk to us about an effective partnership and such partnerships will continue to be a priority for DEBRA International.

EB Without Borders

EB Without Borders (EBWB) is a key initiative of DEBRA International. Our focus is on helping patients, families, and health professionals living or working with EB in countries where there is little or no support, and to help establish national DEBRA groups.

Our EBWB team is a diverse international group whose members come from national DEBRA groups in Spain, Chile, Slovenia, Croatia, Singapore, New Zealand, and Belgium, along with our associate members who are experienced working across borders, cultures, and economic systems. These Regional Ambassadors have specific regions and provide guidance and mentoring support to individuals, as well as mentoring recently formed, small, or struggling existing national DEBRA groups. We encourage the partnership with more established national DEBRAs.

Networks

EBWB now has members in EURORDIS, APARDO, RADIORG, and RD1. Inclusion in these rare disease umbrella organisations is proving to be valuable in extending our range of contacts; we are exploring ways of partnering with national rare disease groups in countries without existing DEBRAs. Increasingly EBWB is providing a pivotal role in connecting those new to the EB world, whether a healthcare professional, patient, or family member to information and the EB community. Requests for information can also come from countries with existing DEBRAs and from people who have much experience with EB who have not been aware of the extent of international expertise. As a rare disease, continuing to forge these links benefits all sectors of EB experience.

EBWB is trialling using various social media platforms as a way of building an EB community that can then take the next step in becoming a registered society.

New and emerging DEBRA groups

DEBRA chapters have recently formed in India, Turkey, Tunisia, Algeria, Albania, and Sri Lanka. We expect these to be followed in the near future by Hong Kong, Bolivia, and Pakistan. EBWB are also working with EB support groups in Cuba and Vietnam.

Focus on Asia

EBWB interest in Asia over the last few years will be in evidence at the DEBRA International Congress 2017 as it is expected there will be representatives from Japan, Singapore, Malaysia, China, Hong Kong, India, Sri Lanka, and Taiwan.

Work to build capacity in India was undertaken by our EBWB Regional Ambassador, Ritu Jain, travelling to Delhi, Chandigarh, and Kolkata to better understand the challenges faced by DEBRA India and to bring patients and clinicians together. EBWB also funded the training of a nurse from Singapore to improve EB care in the region.

Projects

The development of Low Resource Guidelines continues to be a priority for EBWB. This requires a multi-disciplinary approach needing input from a wide variety of sources, particularly families and EB nurses.

EBWB are continuing to drive the development of a clinical advice and nursing support team.

Lea Prujean

EBWB International Coordinator

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Lea Prujean

EBWB International Coordinator

International EB Patient Registry Project

There have been some exciting developments since our last update on the International EB Patient Registry Project.

Work began on collating various datasets from EB registries around Europe. These datasets have been used to complete the first phase of a mapping exercise to identify a consensus dataset, which will be made freely available to any clinical centre wishing to develop or update an EB registry. Our thanks go out to those clinical centres who shared their datasets with us. In order to facilitate the central sharing of data, we are working to identify a core dataset from the larger consensus dataset, which would be mandatory for clinical centres to collect information on.

The consensus dataset has been incorporated into a demo EB registry, which can be viewed here: http://bit.ly/EBRegistryDemo. We encourage clinicians to log in, add fictitious patients with fake data, play around with it, and let us know your views. Centres who wish to adopt the IT platform for this system will not have to pay development costs, which have been funded by the Irish Skin Foundation, although smaller costs relating to implementation and maintenance will apply.

The first meeting of the International EB Patient Registry Governance Committee was held in Salzburg during the EB2017 and EB-CLINET conferences. The Committee – whose membership, among others, comprises of representatives from participating clinical centres, DEBRA, the ERN-Skin, and the Irish Skin Foundation – will focus on reviewing and refining the consensus dataset; defining the best approach for data storage and security, and patient consent; as well as other topics related to governance. One of the outcomes of the meeting was the consensus that the appointment of a registry co-ordinator will be of benefit to driving the project forward. DEBRA International will lead on exploring funding options in order to bring a co-ordinator on board.

We welcome interest from anyone who would like to find out more about the Registry Project, the Registry Co-ordinator role, and participating in the Governance Committee so please do not hesitate to get in touch.

Olivia Mullins
Communications

Good communication can bring the most widespread community together. We share information on the latest medical research, advances in care, events and conferences, and the latest news from our member groups. We strongly welcome news items so please do not hesitate to get in touch to share your stories!

In 2018 we will look to build on our achievements from 2017 and modernise our communication tools bringing a fresh new appearance to DEBRA International.

Newsletter

The DEBRA International newsletter was relaunched in December 2016 with editions released on a bi-monthly basis. A recent swap to another supplier has allowed us to create newsletters with vibrant and dynamic layouts, showing to significantly increase readership well above the industry average. Keep up to date by signing up to the newsletter here: http://bit.ly/DEBRAInternationalNewsletter.

Website

We are excited to announce that 2018 will see the launch of a new DEBRA International website. The move to a different platform will allow for additional features and significantly improve the user experience. The website is our core communication platform and main window to the world. It provides EB and DEBRA-related information to patients, medical professionals, researchers, as well as our member groups.

Social Media

Our presence on social media continues to grow and outreach, with a company page on LinkedIn being a recent addition. Since its creation last year, the number of Twitter followers has nearly doubled and those on Facebook have increased by almost 50%. The new Research Involvement Network (RIN) Facebook group has also begun to draw in a more specific audience interested in becoming involved in EB research and the CPGs. The Facebook Messenger system continues to be a vital tool, connecting people with the EBWB team in the absence of other available communication tools. Work will continue throughout 2018 to boost our profile and connections across these platforms.

EB Awareness Week

The International EB Awareness Week takes place every year between the 25th and 31st October. During this week, DEBRA groups around the world aim to raise awareness and funds for people living with EB. As a special pre kick-off to EB Awareness Week this year, DEBRAs Russia, Chile, and Singapore organised the Butterfly Run, which was held on 8th October to raise awareness of EB and raise funds. We hope this will continue to grow over the coming years with more DEBRA groups taking part. Be inspired by a few examples of other awareness campaigns on the DEBRA International website: http://bit.ly/EBAwarenessWeek

Small Grants

Each year, DEBRA International holds a Small Grant round for its members. We award grants to support specific projects that will benefit people with EB, and to support members who may not be able to cover the travel and accommodation costs of attending DEBRA International endorsed events. In 2016, a total of €13,550 was awarded to DEBRAs Poland, Chile, India, Turkey, Colombia, and Bosnia and Herzegovina.

DEBRAs Bosnia and Herzegovina and Colombia were awarded with travel grants to attend the DEBRA International Congress in Zagreb, Croatia.

DEBRAs Poland, Chile, India, and Turkey were awarded with project grants. To view the full reports, please visit http://bit.ly/DEBRAInternationalSmallGrants.

DEBRA Chile

IX International Symposium of EB

The main objective of the Symposium of EB (held every 2 years in Santiago) is to educate patients and healthcare professionals on clinical care and research on EB. This grant funded the travel costs of 2 of the speakers.

DEBRA India

Comprehensive Management of EB – a Care and Support Programme

This grant funded software to maintain a patient and clinical data registry, the registration of DEBRA India as a charity, EB kits for wound care management as part of a comprehensive care for EB patients across the state of Karnataka.

DEBRA Poland

‘Summer for Butterflies’ Camp

This grant helped fund a camp for members. There was the opportunity to develop their knowledge of EB care with presentations provided by healthcare professionals, participate in fun activities such as canoeing, and socialise with other EB families.

DEBRA Turkey

Distance Learning Media for Wound Care and FAQ in EB Patient’s Life

Project still ongoing

To find out more information on our Small Grants and how to apply, visit http://bit.ly/DEBRAInternationalSmallGrants.
## Profit & Loss Statement
### January 1st 2016 - December 31st 2016

<table>
<thead>
<tr>
<th></th>
<th>2016 (EUR)</th>
<th>2015 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Revenues</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>a) Membership Fees</strong></td>
<td>50,450.00</td>
<td>48,078.20</td>
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<td><strong>b) Other Revenues</strong></td>
<td>100,597.07</td>
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<tr>
<td>Donations</td>
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<tr>
<td>EB Care registry earnings</td>
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<td><strong>Total Revenues</strong></td>
<td>151,047.07</td>
<td>84,911.20</td>
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<tr>
<td><strong>2. Other Income</strong></td>
<td></td>
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</tr>
<tr>
<td><strong>a) Income from the reversal of accruals</strong></td>
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<td>256.00</td>
</tr>
<tr>
<td><strong>3. Other Expenses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>a) Others</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communications</td>
<td>26,449.70</td>
<td>7,170.57</td>
</tr>
<tr>
<td>Clinical Practice Guidelines</td>
<td>43,513.98</td>
<td>66,155.93</td>
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<tr>
<td>EB Without Borders</td>
<td>69,963.68</td>
<td>73,748.50</td>
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<tr>
<td><strong>Total Other Expenses</strong></td>
<td>5,241.33</td>
<td>16,044.42</td>
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<tr>
<td><strong>Research</strong></td>
<td></td>
<td></td>
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<tr>
<td>Professional training</td>
<td>4,230.00</td>
<td>800.00</td>
</tr>
<tr>
<td>Small grants</td>
<td>13,550.00</td>
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<td><strong>Total Research</strong></td>
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<td>11,077.52</td>
</tr>
<tr>
<td><strong>Staffing Costs</strong></td>
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<tr>
<td>Staffing on costs</td>
<td>21,043.96</td>
<td>0.00</td>
</tr>
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</table>
### Profit & Loss Statement

**January 1st 2016 - December 31st 2016**

<table>
<thead>
<tr>
<th>3. Other expenses (contd.)</th>
<th>2016 (EUR)</th>
<th>2015 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel, Mileage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel costs</td>
<td>3,038.74</td>
<td>4,963.75</td>
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<tr>
<td>Other expenses</td>
<td>0.00</td>
<td>2,564.39</td>
</tr>
<tr>
<td>Transaction Costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial transaction fees</td>
<td>1,364.01</td>
<td>1,465.80</td>
</tr>
<tr>
<td>Membership Fees</td>
<td>525.00</td>
<td>625.00</td>
</tr>
<tr>
<td>Internet &amp; website expenses</td>
<td>0.00</td>
<td>15.00</td>
</tr>
<tr>
<td></td>
<td>118,956.72</td>
<td>110,502.38</td>
</tr>
</tbody>
</table>

| 4. Result of association activities | 32,090.35  | -25,335.18 |

| 5. Other interest and similar income | 70.96     | 141.51     |
|                                      | 70.96     | 141.51     |

| 6. Financial result | 70.96 | 141.51 |
|                     | 70.96 | 141.51 |

| 7. Loss from operating activities | 32,161.31 | -25,193.67 |
|                                  | 32,161.31 | -25,193.67 |

| 8. Taxes on income | 17.74 | 35.38 |
|                   | 17.74 | 35.38 |

| 9. Net Income | 32,143.57 | -25,229.03 |
|              | 32,143.57 | -25,229.03 |

| 10. Profits carried forward from the previous years | 126,619.07 | 151,848.12 |
|                                                   | 126,619.07 | 151,848.12 |

| 11. Balance sheet profit | 158,762.04 | 126,619.07 |

### Revenue Generation

**Financial Review**

#### Incoming Resources

- Donations (100,597.07)
- Membership Fees (50,450.00)

#### Outgoing Resources

- Membership Fees (525.00)
- Transaction Costs (1,364.01)
- Travel, Mileage (3,038.74)
- Staffing Costs (21,043.96)
- Legal & Consulting Costs (5,241.33)
- Research (17,780.00)
- Clinical Practice Guidelines (26,449.70)
- EB Without Borders (43,513.98)