Working Together for People Living with EB
Dear DEBRA Members,

I am really glad to see that the past year has been rich of activities oriented to improve the lives of all those living with EB and their families. This report covers just a small part of what has been delivered on the main areas or Debra International wider accountabilities.

The details of the main actions are better defined in the following pages. I just want to mention the further steps that have been taken to improve the clinical research, with the approval of the new Psychosocial Best Practice Guideline and the activities started on international EB Registries with an important meeting held in Dublin earlier this year.

We are continuing to grow with more Countries from all over the World who are joining our network. At the same time, we have secured our presence in the most important international rare disease associations, including the E-PAG, Patients Advocacy Groups at the ERN - the European Reference Network for rare diseases created by the EU this year.

There is still a lot to do and it is important that we stay united towards the same objective of supporting all the people suffering from EB, to improve their quality of life today and ultimately find a cure.

On behalf of the Executive Committee, I want to thank all the people who contributed in many different ways to deliver this year achievements, the Members, the CEO, all Debra friends and the many other volunteers without whom everything we do could never happen.

My best regards,

Dr Cinzia Pilo
President, DEBRA International

“Our vision is to ensure that people living with EB have access to the best quality support and medical care, while also funding development of effective treatments and cures for EB”

With a membership of around 50 National groups, the membership has the following priorities:

- Clinical Practice Guidelines
- Communications
- EB Without Borders (Mentoring)
- Professional Training & Development
- Operations & Administration
- Small Grants Scheme

Our Achievements

Over the years, our achievements include:

- In promoting care for people living with EB, the international focus allows the development of better clinical care by sharing expertise and best practice and by promoting opportunities for Joint training.
- The organisation of clinical trials also depends heavily on these international collaborations. Progress in research and access to clinical care globally can be affected positively by this participation and guidance by the patient lead support group.
- The commencement of a psychosocial guideline.
- The organisation of clinical trials also depends heavily on these international collaborations. Progress in research and access to clinical care globally can be affected positively by this participation and guidance by the patient lead support group.
- Clinical Practice Guidelines on Dental Care, Wound Management, Pain Management and Cancer Guidelines have been completed. Nutrition guidelines on constipation management due soon along with the commencement of a psychosocial guideline.
- Assistance in setting up the International wider accountabilities.
- As another busy year for all comes to an end it is a great opportunity to reflect on the achievement and progress of the last year. The work of DEBRA International is not possible without the great in-kind support received from member countries along with the countless volunteer hours of the dedicated Executive team. Our sincere thanks to all of you.
- Dedicated resources have been taken on to help with the Clinical Guidelines to continue the quality work being done in that area. I also look forward to welcoming our new Business Manager who is the first full-time staff appointment to DEBRA International and introducing them at the International conference in Zagreb, Croatia in September. It is vital that in order to continue to professionalise and improve support for our member countries and the families that are supported we need to resource the organisation appropriately and this is a huge step forward in our continuous improvement plans.
- Earlier this year for personal reasons I have had to resign from my paid role as CEO for DEBRA international and have since been fulfilling the volunteer CEO acting role at the request of the Executive Team. I would like to thank everyone for their support and willingness to share their various experiences with me while undertaking the role. I look forward to supporting DEBRA International and seeing the organisation continue its important work.

Executive Officer Report

Michael Fitzpatrick
CEO (Acting)
DEBRA International
The Role of the Executive Committee

The Executive Committee has representatives from National DEBRAs. Committee Members are elected on a rotational basis every three years and in line with good governance the charity is committed to accountability and transparency for its decisions and activities. Committee members have responsibility for setting the strategic direction as well as directing the activities of the organisation. The Committee meets annually at the DEBRA International conference, has monthly conference calls and also devote a day to setting out its aims for the following 12 months.

DEBRA International Work Streams

The key priorities for the organisation are driven by the leaders of the following work streams:

- **Research**
  - Improve our understanding of EB to create new concepts for treatment
    - Through ‘discovery and therapeutic-concept’ research
  - Improve clinical care through research
    - Expand the evidence-base for symptom relief and clinical practice through research
  - Develop disease-modifying therapies
    - Research to develop therapies targeting underlying disease mechanisms
  - Develop our future EB research community
    - Support next generation of researchers; and infrastructure to support their work
  - Foster partnerships to develop and deliver treatments
    - Increase awareness of our research and opportunities
    - Increase research capacity by working in partnership

- **Patient Care**

- **External Partnerships**

- **Mentoring**

- **Communications**

- **Revenue Generation**

DEBRA International Research Strategy 2015 - 2019

Over the past year, we have launched several new initiatives in line with priorities identified for the 2015 – 2019 DEBRA International Research Strategy.

The DI ‘Clinical Research Program’ call in 2015 welcomed proposals for clinical studies or clinical trials for treatments that address either the underlying causes of EB, or its clinical consequences, or symptom-relief.

From an initial nineteen outline applications received, three clinical trials were recommended in December 2016 for funding.

One of these is already underway, looking at a drug treatment to reduce scar formation in RDEB – an important goal, to reduce debilitating contractures. This drug is already widely, and safely, used in treating high blood pressure; such ‘repurposing’ of drugs is a growing area of research and may be expected to yield important drugs for EB.

Two further research projects were funded by DEBRA Austria from the ‘ordinary’ Spring call in 2016: a novel approach to RDEB gene therapy in Spain; and a US project looking at a new diagnostic approach that should help people with clinical symptoms of EB who lack an identified genetic cause.

As with the Clinical Call, DEBRA’s ‘Patient Panel’ – a group of people with any type of EB and a committed interest in research – provided informed comment on proposals for researchers to consider in the design of their research and clinical trials. (We would always welcome additional Patient Panel members, so please get in touch if interested.)

New partnerships are important for therapy development, and DI has continued to reach out to like-minded potential partners, in other charities, academia and industry. As a result of this, DEBRA Austria has this year developed a collaboration with a Belgian charity Vlinderkindje that focuses on EBS Dowling Meara, to support research on iPSC therapy for EBS-DM in the USA.

DEBRA International continues as a patient-organization partner in the EU-funded consortium project ‘GENEGRAFT’, developing gene therapy for RDEB, with partners in France, UK, Spain, Italy and Germany. The project has received a further extension, and is now progressing towards a clinical trial. DI has also agreed to act as patient-organization partner in a further two applications from consortia for ‘Horizon 2020’ EU funding – this helps to ensure that the priorities of people with EB are taken into consideration in the design and execution of projects.
Relationships continue to be forged with biopharma and healthtech companies. Over the past year, DI input facilitated industry-funded clinical trials for three new topical treatments for symptom relief; discussions are underway for future collaborations in gene, cell and drug therapies.

To maximize effectiveness of research collaborations with industry as a whole, and to ensure that we are meeting industry needs, and vice versa, we are in the process of creating a DI ‘Industry Partners Panel’, which will hold its first meeting in Spring 2017: the response from companies approached to date for this information exchange process has been universally enthusiastic.

Driving research to clinical application requires many additional activities. One of the first such projects is “PEBLES” – (Prospective Epidermolysis Bullosa Longitudinal Evaluation Study), led by Professor Jemma Mellerio in London. This study was initially funded in 2013 to document the natural, ideally life-time, course of RDEB, and is the largest of all the proposed ERNs. It will initially focus on 8 groups of conditions, one of which is EB, and EB registries. Under the leadership of Prof. Christine Bodemer, an application for an ERN focused on rare and undiagnosed skin conditions, ERN-Skin, has been submitted. The network includes 56 partners from 18 countries and is the largest of all the proposed ERNs. It will initially focus on 8 groups of conditions, one of which is EB, and EB features strongly throughout the application.

DI is well represented in the ERN-Skin, with staff or Executive Committee members participating in the associated European Patient Advisory Group (e-PAG), the Research Working Group and the sub thematic group on EB.

An opportunity has arisen through an EU call to establish rare disease European Reference Networks (ERNs), “groups of highly specialised providers across the EU”. The ERNs will facilitate improved care through the sharing of expertise, increased opportunities for research and improved health technologies, including patient registries. Under the leadership of Prof. Christine Bodemer, an application for an ERN focused on rare and undiagnosed skin conditions, ERN-Skin, has been submitted. The network includes 56 partners from 18 countries and is the largest of all the proposed ERNs. It will initially focus on 8 groups of conditions, one of which is EB, and EB features strongly throughout the application.

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Clinical Practice Guideline Initiative

Clinical Practice Guideline Initiative

DEBRA International is undertaking a long-term initiative to develop clinical practice guidelines for EB, in order to improve the clinical care of people with the condition. It is unusual for the development of clinical guidelines to be led by a patient organisation but, in the case of a rare disease such as EB, it is unlikely that guidelines would be developed without the drive of patients.

The past year has been both busy and successful for the initiative. In February Dr. Kattya Mayre-Chilton was appointed to carry out a scoping project to investigate how best to develop future EB guidelines and how to support the clinicians and patients who participate in developing them. The project helped to consolidate the knowledge gained to date and far exceeded its initial goals. Over its course, big steps were taken to progress and strengthen plans for many individual guidelines for various aspects of EB clinical care.

Guidelines are needed for at least 20 aspects of EB clinical care. With 4 guidelines published so far we have a long way to go. We are very enthused by the progress we have been able to make this year however and are very grateful for the support of the community.

9 new guidelines were initiated or progressed from an early stage. Funding permitting, we hope to see further progress in the development of these guidelines over the coming years.

For one of those, which will focus on the psychosocial aspects of EB, funding has been committed by DEBRA Norway, in memory of Heidi Ellingsen Siseth, for which we are very grateful.

Kattya Mayre-Chilton has recently been appointed, to act as Clinical Practice Guideline Coordinator/Psychosocial CPG Project Manager.

Dr. Avril Kennan

Clinical Practice Guideline Project Lead

Kattya Mayre-Chilton, PhD

Clinical Practice Guideline Coordinator/Psychosocial CPG Project Manager

Highlights

- 91 people responded to a survey of clinicians, patients and care-givers. They helped us to understand the priorities for clinical guidance in EB and to identify people who can contribute their knowledge and expertise to develop guidelines.
- Over the course of the scoping project we engaged in discussion with over 200 people, many of whom have committed to being involved in the development of one or more guidelines.
- We listened to the challenges for guideline leaders and put additional supports in place for them, including detailed steps on how to develop an EB guideline.
- 9 new guidelines were initiated or progressed from an early stage. Funding permitting, we hope to see further progress in the development of these guidelines over the coming years.
- For one of those, which will focus on the psychosocial aspects of EB, funding has been committed by DEBRA Norway, in memory of Heidi Ellingsen Siseth, for which we are very grateful.
- Kattya Mayre-Chilton has recently been appointed, to act as Clinical Practice Guideline Coordinator and, one day a week, will provide support to the guideline developers across the various clinical topics and will further facilitate implementation of recommendations from the scoping project.
External Partnerships

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

National DEBRAs advocate on behalf of people with EB with their own national institutions. DEBRA International’s role is to advocate regionally and internationally on issues with an international dimension. In a globalised world, many policy decisions made by international institutions affect people with EB. In addition, the EB Patient Registry Project

For many years the EB community has recognised the need for an international patient registry. While there are many different approaches to EB registries and many EB registries in existence, the challenge has always been to coordinate efforts, to the extent that sharing of data becomes possible. This will be invaluable in many ways, including supporting recruitment for clinical trials, providing evidence for advocacy and facilitating research. International collaboration for that purpose has, so far, been challenged by issues relating to data protection, interoperability and funding. However, with progress in technology and with very welcome seed funding from the Irish Skin Foundation, we are now at a point where it might be possible to overcome these issues.

Working closely with the Irish Skin Foundation, EB-CLINET and the ERN-Skin DEBRA Ireland and DEBRA International hosted a meeting in Dublin in early July to discuss the future of EB registries. The Irish Skin Foundation have been developing ambitious plans for a number of dermatology patient registries, one of which will focus on EB, as a model for rare disease. The aim of the meeting was to bring together leaders from the European EB community and other experts in EB registries to progress these plans and investigate the potential for collaboration. In order to ultimately share information, each clinical centre involved needs to capture the same information on the most important patient details and a major purpose of the meeting was to find a way to agree on the best approach to this. Information is now being used to shape a consensus core dataset. Very importantly, individual centres will also have the flexibility to capture additional information, should they require it for their clinical care or research needs.

The meeting was a great first step in what will hopefully be a long-term project. It will involve a series of steps that will enable the growth of a network of registries, first in Europe and then beyond. It will embrace registries that already exist, while also offering a technical solution to centres hoping to establish a registry for the first time. Data will initially be collected locally and then anonymised and shared centrally. All the while, there will be a focus on how this initiative can support the ERN-Skin and on how to make the registry financially sustainable in the long term.

We are eager to be as inclusive as possible and welcome interest from any EB clinical centre that would like to get involved. Please let us know if you would like to know more.

Dr. Avril Kennan

Patient Care

EB Without Borders

The EBWB team is a diverse international group that work to help people with EB and their families and health professionals in countries where there is little support or information about EB. They help to develop and mentor new DEBRA groups. DEBRA groups have recently formed in India, Turkey, Tunisia, Algeria, and Albania. A DEBRA Vietnam and a DEBRA Sri Lanka are expected soon.

Anna Kemble Welch is the EBWB Ambassador for the South East Asia and Pacific region. Recently in Ho Chi Minh City, Anna met with volunteers working with EB families. They will work with an EB Children’s club in Hanoi to establish a DEBRA Vietnam. With funding Anna secured from a Rotary group, Sharon Cassidy, an EB Clinical Nurse Specialist, travelled to Sri Lanka and China for EBWB. She worked with families and clinicians, and visited hospitals to give hands-on training, support and advice.

Evanina Makow and Loreto Moore are EBWB Ambassadors for South and Central America and Spanish speaking countries. Loreto travels within the region to speak about DEBRA International and to develop EB capability. This December, Loreto and DEBRA Chile have organised the IX International Symposium on Epidermolysis Bullosa to be held in Santiago, Chile.

Living with EB in impoverished conditions can mean a miserable existence and early death. Using limited resources knowledgeably and with an understanding of good wound-care this can change. A small training team has a huge ripple effect, gives much needed skills and education and transforms lives. We plan to expand the information on the DEBRA International website to include information about how to manage EB at the most basic level where there is no access to modern healthcare.

Lea Prujean

EBWB International Co-ordinator
Communications

Good communications can even bring the most widespread community together. Such is the mission of the DI communications team: to allow for fruitful exchange of ideas and knowledge through a constant flow of information, and to make resources easily accessible for those needing them. While being challenged by lack of personnel over the last year we have endeavoured to keep a baseline of communication activity, with the hope of increasing that activity again in the coming year. In parallel we have substantially increased our social media presence and see that as an important communications tool for the future.

Website

This is our core communication platform: a central hub for the DEBRA community as well as external stakeholders. It provides EB-related information to patients, their families, DEBRA delegates, medical staff, the medical research community and all other groups.

www.debra-international.org

News

News articles include reports on the latest medical research, advances in care and reports on relevant conferences or events and feed not only the website but the newsletter and social media. We strongly welcome stories submitted by member groups and so, if you have a story, or would like your group to feature, please get in touch! A news template is available on the website for your use. Have a look and subscribe to the DI newsletter; you will find a ‘sign up’ button on the homepage of the website.

Social Media

DEBRA International’s social media profile has increased this year with a new edition to the DI family with the introduction of our Twitter page @InterDEBRA. We have 170 followers on the page to date and hope to gain many more and also help to publicise our website more via Twitter. Facebook has made steady growth too in 2016 and we hope this will continue to grow into 2017. So with a full armoury of social media we hope to make many more connections in the year to come. We will also be improving our profile on LinkedIn in the coming year so we can reach out to business users more and increase our networking potential.

International EB Awareness Week

The IEBAW takes place in the last week of October each year. Our work simply couldn’t happen without amazing supporters who raise the money that funds it. During this week, DEBRA groups around the world aim to raise awareness and funds for people living with EB. Be inspired for the upcoming IEBAW by a few examples of awareness campaigns on the DI website: www.debra-international.org/news-and-events/eb-awareness-week-eb-awareness-day.html.

Introducing

Olivia Mullins is joining DI in the newly created role of Business Manager on 19th September, based in the UK. She has a first class Honours degree in Spanish with proficiency in Italian, and has most recently worked as a Senior Intellectual Property Services Coordinator, project managing the translation process of IP related documents. With her advanced language skills and strong organisational abilities, she is a welcome addition to the DI team, providing invaluable administrative support.
### 1. Revenues

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>a) Membership Fees</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Membership Fees</td>
<td>48,078.20</td>
<td>49,392.00</td>
</tr>
<tr>
<td>Research co-funding</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>48,078.20</td>
<td>49,392.00</td>
</tr>
<tr>
<td><strong>b) Other Revenues</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other revenues</td>
<td>3,100.57</td>
<td>5,185.93</td>
</tr>
<tr>
<td>Donations</td>
<td>10,179.66</td>
<td>10,557.27</td>
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<tr>
<td>EB Care registry earnings</td>
<td>23,552.77</td>
<td>12,000.00</td>
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<tr>
<td><strong>Total</strong></td>
<td>36,833.00</td>
<td>27,743.20</td>
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<tr>
<td><strong>Total Revenues</strong></td>
<td>84,911.20</td>
<td>77,135.20</td>
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### 2. Other Income

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
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<tbody>
<tr>
<td><strong>a) Income from the reversal of accruals</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dissolution other accruals</td>
<td>256.00</td>
<td>843.00</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>256.00</td>
<td>843.00</td>
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### 3. Other Expenses

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<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>a) Others</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distribution costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communications</td>
<td>420.00</td>
<td>19,807.78</td>
</tr>
<tr>
<td>Best practice guidelines</td>
<td>7,170.57</td>
<td>0.00</td>
</tr>
<tr>
<td>EB without borders</td>
<td>66,155.93</td>
<td>35,582.98</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>73,746.50</td>
<td>55,390.76</td>
</tr>
<tr>
<td>Legal &amp; Consulting costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal &amp; consulting costs</td>
<td>14,623.92</td>
<td>5,082.35</td>
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<tr>
<td>Bookkeeping costs</td>
<td>1,420.50</td>
<td>1,399.50</td>
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<tr>
<td><strong>Total</strong></td>
<td>16,044.42</td>
<td>6,481.85</td>
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<tr>
<td>Research</td>
<td></td>
<td></td>
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<tr>
<td>Professional training</td>
<td>800.00</td>
<td>9,332.88</td>
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<tr>
<td>Small grants</td>
<td>10,277.52</td>
<td>11,930.00</td>
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<tr>
<td><strong>Total</strong></td>
<td>11,077.52</td>
<td>21,262.88</td>
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### 4. Result of association activities

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
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</thead>
<tbody>
<tr>
<td>Result of association activities</td>
<td>-25,335.18</td>
<td>-9,210.84</td>
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</table>

### 5. Other interest and similar income

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
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</thead>
<tbody>
<tr>
<td>Interest proceeds from bank credits</td>
<td>141.51</td>
<td>165.75</td>
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### 6. Financial result

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial result</td>
<td>141.51</td>
<td>165.75</td>
</tr>
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</table>

### 7. Loss from operating activities

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Profit from association activities</td>
<td>-25,193.67</td>
<td>-9,045.09</td>
</tr>
</tbody>
</table>

### 8. Taxes on income

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capital gain tax</td>
<td>35.38</td>
<td>41.44</td>
</tr>
</tbody>
</table>

### 9. Net Income

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Net income</td>
<td>-25,229.05</td>
<td>-9,086.53</td>
</tr>
</tbody>
</table>

### 10. Profits carried forward from the previous years

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Profit carried forward</td>
<td>151,848.12</td>
<td>160,934.65</td>
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</table>

### 11. Balance sheet profit

<table>
<thead>
<tr>
<th></th>
<th>2015 (EUR)</th>
<th>2014 (EUR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance sheet profit</td>
<td>126,619.07</td>
<td>151,848.12</td>
</tr>
</tbody>
</table>
Revenue Generation

Financial Review

DEBRA International has a relationship with CAP Partners who act as fundraisers for the organisation in seeking corporate sponsorship and gift in kind support from the healthcare industry.

Incoming Resources

- Donations (10,179.66)
- EB Care Registry (23,552.77)
- Membership Fees (48,078.20)

Other Revenues (3,100.57)

Outgoing Resources

- Internet (15.00)
- Communications (420.00)
- Membership Fees (625.00)
- Professional Training (800.00)
- Bookkeeping Costs (1,420.50)
- Financial Transaction Fees (1,465.80)
- Other Fees & Costs (2,564.39)
- Travel Costs (4,963.75)
- Best Practice Guidelines (7,170.57)
- Small Grants (10,277.52)
- Legal & Consulting Costs (14,623.92)
- EB Without Borders (66,155.93)