

**ANNUAL REPORT 2016**

**STICHTING EUROPEAN CLEFT ORGANISATION**

**DEN HAAG**

## CONTENTS

	Page
Content	1
Compilation report	2
General	3
Balance sheet as at per 31 December 2016	5
Income & expenditure account for the year 2016	6
Notes to the Financial Statements	8
Annual report confirmation	12

To the board of Stichting European Cleft Organisation  
Verrijn Stuartlaan 28  
2288 EL Rijswijk

Subject : Annual report 2016  
Reference : 0832/2016  
Date : Den Haag, 4 October 2017

Dear Sirs,

We hereby send you the annual report regarding the financial statements for the year 2016 of your foundation.

### **Compilation report on financial statements**

#### **Introduction**

In accordance with your instructions, we have compiled the financial statements 2016 of Stichting European Cleft Organisation, which comprise the balance sheet as per 31 December 2016 and the profit & loss account for the year ended as per 31 December 2016.

#### **Board's responsibility**

The distinctive feature of the compilations engagement is that we compile financial information based on information provided by management of the entity. Management is responsible for the accuracy and completeness of the information provided and the financial statements based thereon.

#### **Our responsibility**

Our responsibility is to perform our engagement in accordance with Dutch law, including profession and ethical requirements issued by the Dutch law authorities and related branche organisation. In accordance with the professional standard applicable to compilation engagements, our procedures were limited primarily to gathering, processing, classifying and summarizing financial information. Furthermore we have evaluated the appropriateness of the financial policies which are used to compile the financial statements, based upon the information provided by the management. The nature of our procedures do not enable us to express any assurance on the true and fair view of the financial statements.

#### **Confirmation**

Based on the information provided to us, we have compiled the financial statements in accordance with financial principles generally accepted in The Netherlands.

**General**

**Activities**

The activities of Stichting European Cleft Organisation are mainly improving healthcare concerning cleft, sharing information about treatment, raising funds.

**Board**

The board of the foundation:

President : Mr. N. Mercer

Treasurer : Mr. mr. A.V. Hardoar

**Tax**

The foundation has no taxable activities.

Therefor the foundation has not an obligation to pay Value Added Tax (VAT).

**ANBI status**

The organisation received the ANBI status issued by the Dutch Authorities.

Your sincerely,



J.B. Kuper  
Administratiekantoor Kuper

**FINANCIAL STATEMENTS 2016**

## BALANCE SHEET AS PER

	<u>31 December 2016</u>	<u>31 December 2015</u>
	€	€
<b>ASSETS</b>		
<b>Computers</b>		
Computers	4.341	4.341
Depreciation	<u>-2.146</u>	<u>-1.329</u>
	2.195	3.012
<b>Debtors</b>		
BG Plovdiv Project	0	41.011
Resurgens Foundation Project Funds	<u>9.464</u>	<u>0</u>
	9.464	41.011
<b>Current assets</b>		
ING bank nr. 4466591	3.077	8.962
ING bank nr. 4466591 deposit	117.132	84.282
Petty cash	<u>301</u>	<u>0</u>
	120.510	93.244
<b>Receivebles</b>		
Assurance board	654	0
Interest ING bank nr. 4466591 deposit	<u>151</u>	<u>350</u>
	805	350
	<u><u>132.974</u></u>	<u><u>137.617</u></u>

BALANCE SHEET AS PER	<u>31 December 2016</u>	<u>31 December 2015</u>
	€	€
<b>EQUITY AND LIABILITIES</b>		
<b>Capital</b>		
Balance as per 1 January	127.030	97.941
Result	<u>3.083</u>	<u>29.089</u>
Balance as per 31 December	130.113	127.030
<b>Current Liabilities</b>		
<b>Creditors</b>	1.528	0
<b>Accrued Expenses</b>		
Bank costs	33	34
Wage	0	443
Wage Tax	0	861
Travel	0	419
Rent	0	333
Accountant	1.300	2.032
ESF Partners	<u>0</u>	<u>6.465</u>
	1.333	10.587
	<u><u>132.974</u></u>	<u><u>137.617</u></u>

## INCOME &amp; EXPENDITURE AS PER

	2016	2015
€	€	€
<b>Donations</b>		
Resurgens/Esperanza Foundation	134.864	128.409
ESF Scientific Programme	6.465	0
ESF EuroCleftNet grants	5.218	0
General donations	772	9.732
Travel Allowances-network partners	2.077	3.200
Erasmus IHEM	9.601	0
Erasmus FV	0	13.200
Erasmus WL	0	14.124
	158.997	168.665
<b>Projects costs</b>		
Bulgaria	49.131	36.945
ESF Euro Cleft Net Core Funding	11.165	0
ESF/ECO Gateway Project	1.275	0
CEN Guidelines Implementation	2.248	0
Cost Action	944	1.243
Lithuania	0	610
Latvia	0	1.136
Face Value Project	1.326	790
When Looks Project	1.636	679
IHEM Project	1.172	500
Exploratory Country Missions	795	0
Conferences & Training	5.303	2.224
Educational Workshops and Training	608	2.430
Project Planning & Coordination	0	50.000
G. Davies	60.000	0
E. Southby	4.167	0
Fundraising & Presentation	425	0
Travel & accommodation	134	7.031
	140.329	103.588
<b>Operating results</b>	18.668	65.077
Transporting	18.668	65.077



**INCOME & EXPENDITURE AS PER**

	<u>2016</u>	<u>2015</u>
	€	€
Transporting	18.668	65.077
<b>Expenditure</b>		
PR & Fundraising	0	10.000
Salary Personel	0	5.199
Social Security Costs	0	867
Assurance personel	0	18
Conferences & Training	0	4.203
Travel & Accomodation general	3.151	5.866
Rent office	3.993	3.333
Subscriptions	351	442
Computercosts	70	387
Legal and Professional Costs	0	453
Accountant & Administration	4.781	2.735
Consulting Costs	151	0
Office costs	389	1.017
Website costs	691	629
Bankcosts	307	372
Cash difference	6	0
Assurance Board	1.020	0
Depreciation computers	817	817
	<u>15.727</u>	<u>36.338</u>
<b>Operating results</b>	2.941	28.739
<b>Financial results</b>		
Exchange difference	-9	0
Interest deposit	151	350
	<u>142</u>	<u>350</u>
<b>RESULT</b>	<u><u>3.083</u></u>	<u><u>29.089</u></u>

## Notes to the Financial Statements 2016:

### Appendix 1

#### Overview

The European Cleft Organisation is a Dutch based NGO founded in 2008 with full charity tax status (ANBI) in the Netherlands. Its principle aim is to improve cleft care in Europe for all children and adults born with clefts. There is currently a huge disparity in care across Europe and in some countries children born with clefts are needlessly placed in orphanages.

#### Values

We believe all children and adults born with clefts must have:

##### *Equal Opportunities*

The right to a life full of equal opportunities without discrimination.

##### *Quality Care*

The right to access quality care to experience life to their fullest potential.

##### *Patient-centred care*

The right to receive care within a whole person approach which engages from a holistic and multidisciplinary perspective.

##### *Evidenced-based*

The right to benefit from interventions rooted in sound research and best practices.

#### Mission

The European Cleft Organisation (ECO), through training initiatives and a network of partners, creates environments to ensure every family and all children affected by clefts have life-long access to quality care and equal opportunities within our European societies.

#### Vision

Every child with a cleft has lifelong access to quality care and equal opportunities throughout Europe.

#### Approach

- *Awareness Raising* - communicating information which improves understanding of the challenges faced by families, children and adults with a cleft.
- *Policy Change* – dialoguing with government stakeholders to formulate initiatives which increase access to quality health care and equal opportunities for families, children and adults with a cleft.
- *Capacity Building* – through training, strengthening organizations'/hospitals' ability to deliver quality health care and support for families, children and adults with a cleft.

- *Collaboration* – networking with organizations to exchange information, share resources, and enhance each other's capacity to advance the cause of for families, children and adults with a cleft.

### **Achievements to date**

The European Cleft Organisation has two paid staff member (Executive Director and Training Manager) and the outputs to date have been highly impressive given this low investment in human resources:

- \* Nine-year operational management of pilot programmes in Bulgaria, developing a national centre of excellence in cleft care in Plovdiv, working alongside a local partner. Training and developing networks of nurses and speech therapists. Reducing abandonment of babies with clefts.
- \* Development of European guidelines in early cleft care (with European Committee for Standardisation (CEN, Brussels - see below).
- \* Facilitating nurse training in Bulgaria, Latvia, Lithuania, Romania, Serbia, Spain and overseeing development of RomaniaCleft, the first professional cleft association in Romania. Greece and Slovenia have requested training for 2017 and we are currently developing a more rigorous partnership training agreement with countries to ensure new skills are implemented in day to day practice.
- \* Development of web directory for cleft services in Europe (European Cleft Gateway) a resource for cleft professionals and patients. Currently over 100 centres represented and. Thanks to a grant from the European Science Foundation (EUROcleftNet programme) the Gateway will be extensively rebuilt during 2017 to make it more user friendly and accessible to clinicians, researchers and patients alike. There has been interest in this from some major cleft organisations globally and with further funding it may provide a model that could be used beyond Europe.
- \* Partners in five EU-funded collaborations - COST 'Appearance Matters', ESF 'EUROcleftNet', Erasmus Plus 'When Looks get in the Way', 'Face Value' and 'IHEM' (health education module). At the end of 2016 we submitted a major application for a new and ambitious COST initiative looking specifically at equal access to cleft care across Europe and in 2017 we plan further Erasmus applications, including a specific proposal around the development of a cleft nursing training programme.
- \* Coordinated 2 major European conferences - Plovdiv 2012 (research), Bucharest, 2015 (specialist nursing)

### **Approval of European guidelines in cleft care**

In 2015 member bodies of the European Committee for Standardisation (CEN) approved the guideline report CEN/TR 16824 'Early care services for babies born with cleft lip and/or palate'. The process began in 2011 and the final report has been the result of input from stakeholders in Austria, Belgium, Bulgaria, Estonia, Finland, France, Germany, Lithuania, Spain, Romania and the UK. The process was initiated and coordinated by ECO and the result is a document that can act as a model for early cleft care in countries where no protocols exist. In the longer term this document may have global impact.

DOWNLOAD GUIDELINES: <http://europeanleft.org/download-guidelines/>

### **ECO in numbers**

2017 marks the tenth anniversary of the foundation of the European Cleft Organisation. Here's a look back at some of our achievements in numbers.

**10** - number of years since ECO launched

**1,000,000** – number of people with clefts in Europe

**1,100,000** – population of Brussels

**100** – number of cleft teams represented on our European Directory of cleft services (The Gateway) featuring 400 individual clinicians

**2,158** – number of families attending ECO funded multidisciplinary clinics in Bulgaria 2012 - 2016

**330** – number of children receiving ECO funded outreach therapy and orthodontic care in Bulgaria 2012 - 2016

**189** – number of referrals to ECO funded nurse network in Bulgaria 2013 - 2016

**40%** - the number of parents of children with clefts in Bulgaria advised to send their newborns to orphanages in 2011

**27%** -the number of parents of children with clefts in Bulgaria advised to send their newborns to orphanages in 2016 – after ECDO's interventions and training

**12** – number of countries ECO has partnered with in EU funded projects developing training programmes

**12** - number of languages above training delivered in

**17660** - number of people ECO has reached reached via conferences, workshops, lectures through its EU programmes

**530** – number of front line health professionals attending ECO specialist cleft nurse training courses in 6 countries

**8,521** – number of words in Early Cleft Care Guideline report produced by ECO with the Committee for European Standardisation with agreement by doctors and patients in 12 countries, taking 5 years to put together.

**1,700** - number of downloads of cleft guideline Jan – December 2016

### **Board of Directors**

There were some changes to the Board of Directors in 2016. Founding Member Gareth Davies stood down from his role of Chair and was replaced by long-standing board member, Nigel Mercer, cleft surgeon and former President of the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS). Emma Southby also stood down after being interviewed and appointed as the charity's first Training Manager. Julija Radojčić, a specialist cleft orthodontist from Serbia, joined the board as a representative of our partner projects.

### **Challenges going forwards**

To build on our successes to date and to be able to deliver training to those countries that have requested it, ECO took on its second staff member at the end of 2016. Emma Southby joined us as Training Manager and will develop and extend training programmes across Europe. Her first major task will be to apply for EU funding through the Erasmus programme for specialist nurse training. Should this be successful she will lead partner countries over two years in the development of a downloadable multi-language dedicated training programme in early cleft care.

To sustain the Training Manager post in the longer term ECO needs to develop fundraising strategies on many fronts and build relationships with a wider network of potential funders. There is a need to raise the charity's profile in its home country, the Netherlands and we envisage working more closely with health professionals in the Netherlands during 2017. This will be helped by the fact that the new EU-driven European Network for Craniofacial anomalies and ENT disorders is being coordinated from the Children's Hospital in Rotterdam. ECO is on the Management Board of this new network. Secondly, the 2018 European Craniofacial Congress is being hosted by the cleft team in Utrecht and we will be liaising with Congress organisers in the planning of the event. The cleft team in Nijmegen has also recently expressed an interest in our nurse training activities. All these connections should serve to strengthen our profile and raise our visibility in the Netherlands.

Gareth Davies  
Executive Director

Annual report confirmation

Den Haag, 4 October 2017

President: Mr. N. Mercer

A handwritten signature in black ink, appearing to read 'N. Mercer', with a horizontal line underneath.

Treasurer: Mr. mr. A.V. Hardoar

A large, stylized handwritten signature in blue ink, appearing to read 'A.V. Hardoar', with a long horizontal line extending to the right.