



European Federation of Allergy and Airways
Diseases Patients' Associations

Annual Report

2018

**SHEDDING LIGHT
INTO THE
severity
OF ALLERGY AND
AIRWAYS DISEASES**

Foreword



“While living with severe chronic disease is tough, and the healthcare system and prevention policies still need to truly incorporate supporting quality of life, the strength and resilience of ‘severe’ patients remind us about our love to life and the need to be together.”

Mikaela Odemyr, EFA President

Do you know what **severe** means for people with allergy and airways diseases? It is severe when you are in and out of hospital due to asthma and you do not know what is wrong. It is severe when you live like this for twenty years before you are empowered to take control of your quality of life with asthma. It is severe when you have to scratch until blood, and are not sure if you can face life with atopic eczema. 2018 was a severe year for EFA, together with Members we shed light into the severity of allergy and asthma with patient evidence and awareness activities.

Through the **Severely Asthma!** Project, EFA in collaboration with Members shared the testimonies of six severe asthma patients across Europe to improve the understanding of what it means to live with limited lung function. Through the launch of our report “Itching for Life: Quality of Life and costs for people with severe atopic eczema in Europe” and photo exhibition, we encapsulated the quality of life in severe atopic eczema, portraying the beautiful human beings living **Atopical Lives** in six countries.

In our **Active Patients Access Care Survey**, we asked asthma and chronic obstructive pulmonary disease (COPD) patients from seven countries about their care, diagnosis, involvement in their care and access to prevention, to create Patient Reported Evidence about the current situation and real disease burden of patients. The results will underpin a European campaign to be initiated in 2019 to build leadership for change on allergies and airways diseases.

I am truly proud of the trust and dialogue opportunities that materialised last year. In 2018, our federation was recognised at the highest levels of regional policy-making: we were re-elected to the European Medicines Agency Patients and Consumers Working Party (PCWP); the 68th session of the World Health Organisation Regional Committee for Europe accredited EFA to initiate official

relations as a non-state actor; and we signed a Memorandum of Understanding with the European Academy of Allergy and Clinical Immunology (EAACI), our first bilateral agreement formalising a partnership.

While living with severe chronic disease is tough, and the healthcare system and prevention policies still need to truly incorporate supporting quality of life, the strength and resilience of ‘severe’ patients remind us about our love to life and the need to be together. This is what EFA is all about for me: the permanent opportunity to share, build evidence and take action from a patient perspective, a unique federation of 42 national patient associations, with the patients and families they represent. We altogether form a solid organisation that lead towards actions that improve our lives.

Thank you to our Members and all the volunteer patients who shared their story, lent their expertise or participated in our surveys, sharing our joint vision, and thanks to our key partners acknowledged in this report for believing in it. Thanks to our sustainable funding partners and DG Research and Innovation for supporting our work.

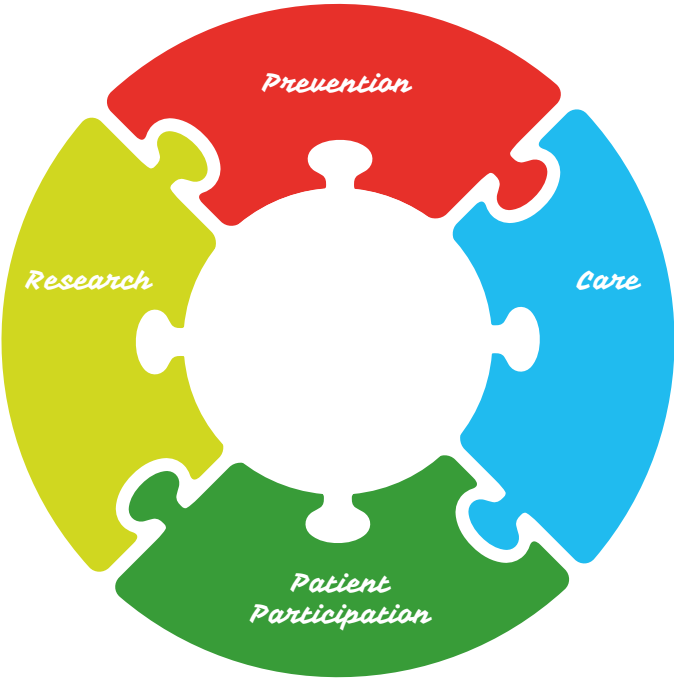
Europe, do more, not less for health! Severely, strong,

Mikaela Odemyr, EFA President

EFA’s 2018 Achievements

- We responded to the official and targeted consultations of the Fitness check of the EU Ambient Air Quality Directives (July)
- We sent our response to the European Commission consultation evaluation the implementation of the 7th EU Environmental Action Programme (July)
- We attended the 1st-ever WHO Air Pollution and Health Conference in Geneva (October)

- We enabled the dissemination of Horizon 2020 project CURE: Eubiosis Reinstatement Therapy
- We became chair of Patient Access Partnership (PACT) (December)
- We are the only patient representative at the European Commission Scientific Panel for Health



- We launched the 1st European Atopic Eczema Awareness Day (September)
- We welcomed one new association from France working on atopic eczema (April)
- 59 patient representatives from 14 Members were trained through our Capacity Building programme webinars (September-December)
- 6 patients’ advocates met 11 Members of the European Parliament in the framework of our Meet & Greet the EU training (January 2019)

- We are official members of the European Medicines Agency (EMA) Patients’ and Consumers’ Working Party and we participated in the EMA Topic Group on Digital Health. EFA patient experts were involved in 2 Scientific Advisory Working Party procedures and the review of 5 Patient Information leaflets on medicines.
- We were elected non-state actors by the WHO Regional Committee for Europe (September)
- We shed light into how severity affects many aspects of daily life with 6 videos from severe asthma patients and a carer from 5 EU countries
- We published the results of the biggest Quality of Life survey of severe atopic eczema patients in 9 European countries (September)
- As the only patient representative within the Steering Group on Influenza Vaccination, we launched a joint Manifesto #EUFightingFlu (April)



Air quality

A better-informed citizenship and the uncovered illegal practices on the respect of air pollution limits have paved the way for a rich debate and attention to the air we breathe. In 2018, EFA engaged in the European Commission assessment of the two **EU Ambient Air Quality (AAQ) Directives** adopted in 2008 and 2004. This procedure, called fitness-check, aimed at evaluating whether the two legislations are suitable for environmental and health protection by the end of 2019. We responded to the consultation and targeted questionnaire stating that given that the pollution levels set by the Directives are above the WHO Air Quality Guidelines and therefore translate into harmful effects towards respiratory health, the future legislation should: (1) restrict current emission levels, (2) include the monitoring of biological particles (pollen) and (3) reinforce the transparency and public information on emissions, targeting the protection and exposure of vulnerable groups.

We were also invited to bring the patients perspective to the first-ever **WHO Conference on Air pollution and Health** celebrated in November in Geneva, a milestone event towards the reduction of air pollution in our planet.

We also contributed to the European Commission evaluation on the **7th Environmental action programme** (2013-2020), regretting the lack of action on a topic that has been on the programme since 2013: indoor air quality.



Tobacco

Tobacco continues to be the largest avoidable health risk in the European Union. It is responsible for many respiratory diseases such as chronic obstructive pulmonary disease (COPD). In 2018 we brought the patient views to the **International Conference of the European Network for Smoking Prevention** (ENSP), of which we are an associate member, where we updated our knowledge on the current tobacco market and tobacco control issues. During the event, we initiated links with the global community seeking to advance to control legislation underpinning human right values.



Food labelling

With the rise of innovative ingredients entering our meals, EFA is closely following the basis to assess the allergenicity risk of the so-called **novel foods**. The authorisation of novel foods is managed by the European Food Safety Authority on which EFA is a registered NGO stakeholder. In 2018, we brought the patient perspective to ImPARAS, the network of scientists studying what makes a protein an allergen (COST Action FA1402).

We also set the scene of the second 'International Symposium on Food Allergens: regulation, management and detection' with a keynote speech advocating that we need **better labelling** to empower patients with food allergy. In a nutshell, EFA demands the establishment of risk thresholds for allergens, to surpass the often misused "may contain" labelling by food operators due to lack of guidance and regulation, and resulting in risk-taking behaviour by food allergy patients.



Healthcare

In 2018, we welcomed the European Commission proposal for a regulation on **Health Technology Assessment** (HTA), a legislation that will contribute to the setting of technology standards for patients accessing healthcare in Europe, and to advance EUnetHTA, an HTA cooperation framework of which EFA is Member. Together with Members we developed a position paper highlighting areas to improve within the HTA proposal, such as the need to improve the involvement of patients in HTA, so that we are consulted throughout the whole evaluation and decision process and not just ad hoc.

As active members of the **#EU4Health campaign**, we contributed to a joint statement: "Europe do More for Health!" signed by 15 organisations pinpointing seven actions the European Commission should plan for the Future of Europe. Collectively we communicated them throughout the year to refrain the European Commission from dismantling the Directorate General for Health and Food Safety in the next 2019-2024 mandate, which would imply the deletion of the health leadership and perspective from the common market.

We also participated in the European Patients Forum's (EPF) first **Nutrition Task force**, launched in February 2018, because nutrition is an essential component of disease management. The resulting EPF Clinical Nutrition Guidelines and Summaries for Patients have specific chapters on food allergy and COPD.



Medicines

Throughout 2018 we continued to represent allergy and airways disease patients at the **European Medicines Agency Patients and Consumers Working Party** (EMA PCWP), and at the EMA Digital Health Topic Group. Patient experts from EFA network took part in scientific working party meetings and were consulted on public information on medicines. We were also honoured to be elected as Chair of the **Patients Access Partnership** (PACT).

Europe is facing a vaccine hesitancy trend. To counter-balance the doubts, the European Commission launched a consultation on strengthened **cooperation against vaccine preventable disease**. EFA response focused on the recommendation of vaccination as a treatment against infections that can be fatal for people living with chronic diseases such as asthma and COPD. EFA is the patient representative of the Steering Group on Influenza Vaccination, a joint action co-chaired by Françoise Grossetête, Member of the European Parliament. In 2018, we launched a 10-point Manifesto calling the EU for more action to increase seasonal influenza vaccination coverage rates in Europe. <http://eufightingflu.com/>



Research

EFA's mandate in the **Scientific Panel for Health** (SPH) under the EU Research Programme Horizon 2020 was renewed in 2018. We contributed to the development of the main SPH output 'Better Research for Better Health', science led vision for EU, outlining how Europe can become a leader, and better organise health research based on the needs of citizens and patients, and ensure the use of the results. We also co-chaired the Panel's workshop Impact of health research for society.



"The EU has the potential to be a world leader in driving a positive change in non-communicable diseases - if it decides to be more ambitious and to invest in research and in sharing best practices between member states."

MEP Anna Záborská (Slovakia, EPP, and Member of the Interest Group on Allergy and Asthma)

#EPAllergyAsthma

<http://www.allergyasthma.parliament.eu>

Encouraging the European Parliament to prevent and ease allergy and asthma

Since 2015, the Members of the European Parliament Interest Group on allergy and asthma, a project led by EFA and the European Academy of Allergy and Clinical Immunology (EAACI) bring the needs of the patients to the top of the EU agenda. In 2018, EFA equipped the Interest Group with a modern visual identity, a new corporate website and a quarterly newsletter to support its activities within the European Parliament, and beyond.

Tackling the issue of "how to overcome the barriers to research in chronic NCDs in Europe? The case of allergy and asthma", three Members of Parliament hosted an event organised by EFA with decision makers involved in EU research. At the meeting, past research achievements and the future necessary steps were discussed.



From left to right, David BORRELLI (Italy, NA) and Nessa CHILDERS (Ireland, S&D) co-hosted the Interest Group event on research for allergy and asthma held in October 2019 at the European Parliament together with Anna ZÁBORSKÁ (Slovakia, EPP).

The upcoming EU elections in May 2019 will increase dynamics within the Interest Group. We see the new composition of the Parliament as a great opportunity to enhance and strengthen the voice of people living with allergy and asthma even more. EFA thanks and appreciates those MEPs who have supported our cause through this Interest Group and who will step down from Parliament. Thank you!



Increasing the visibility of severe asthma



Thanks to Peter, Nadia, Anne, Breda, Pontus and Mikaela for sharing your experience!

While around 30 million Europeans live with asthma, up to 10% suffer of a severe form. The health community is analysing why this proportion of patients do not respond to usual asthma treatments. The objective is to develop medicines that allow patients control their asthma, reduce the symptoms and have a better quality of life.

In World Asthma Day 2018, we launched Severely, ASTHMA! a video series portraying six real severe asthma patients and their families throughout Europe, each bringing a unique insight on diagnosis, care, social and family life, being young with asthma, participating in research and living with

air pollution. Their personal stories are universal in the world of asthma. They have adapted their lives and their stories echo the difficulties in getting the diagnosis and care that empower them. They are an example of resilience and through their videos they address themselves directly to other patients.

With this project we hope to have shed light into the daily impact severity asthma, to increase the awareness among patients that might still lack an accurate diagnosis, and to stress the pressing need to propose all patients with the right solution to their disease as early as possible.



EFA brought the severely asthma video series to the Respiratory Society Congress 2018 and presented it at World Village Auditorium and the Patient Organisation Networking Day.

#SevereAsthma

<https://www.youtube.com/user/EFAADPA/playlists>

"For those with eczema who read this report please know you are not alone. That's what this study shows most powerfully. The feelings and emotions you are experiencing are shared with many people in the same circumstances in many countries. This does not change your symptoms, I know, but it might help to change the way you feel."

Bernd Arents, severe atopic eczema patient from The Netherlands, and Patient Advisor to EFA QoL study

#AtopicalLives

<http://www.efanet.org>

ECZMA
Atopical Lives



EFA Board supporting the launch of the «Itching for Life» report.

Building the European voice of atopic eczema patients

To fill the gap in patient reported picture on quality of life in severe atopic eczema in Europe, in 2017 EFA interviewed 1189 patients from 9 countries on their Quality of Life (QoL) and economic impact on their severe atopic eczema. Though this survey, also a genuine Patient Reported Outcome Measurement (PROM) tool was born: Atopic Eczema Score of Emotional Consequences (AESEC®).

The biggest-ever Quality of Life report on atopic eczema in Europe

1 scientifically validated questionnaire, translated in 8 languages and approved by 9 national ethical committees

1,189 severe atopic eczema patients interviewed from 9 countries: Czech Republic, Denmark, France, Germany, Italy, Netherlands, Spain, Sweden, and the UK

The report 'Itching for Life: Quality of Life and costs for people living with severe atopic eczema in Europe' brings life this data, the true impact of severe atopic eczema and it was launched during the first ever European and Global atopic eczema day.

1 ground-breaking report developed with EFA Members with the Atopic Eczema Working Group, and translated in 9 languages

The report was officially launched during EADV Congress and followed by 261 people physically and online.

Event launch recording available online: www.youtube.com/user/EFAADPA/playlists



'Burden of disease and quality of life of patients with atopic eczema in Europe: Measurement following a survey in 9 European countries' at the International Symposium on Atopic Dermatitis (ISAD), in Utrecht (the Netherlands)



Atopic eczema: the silent suffering of patients' at the European Academy of Dermatology and Venerology (EADV) Congress

2018

April 11-13

June 28

September 13

September 17

'Atopic eczema score of emotional consequences (AESEC): An instrument to measure emotional consequences in adults', at the European Allergy Academy of Allergy and Clinical Immunology (EAACI) Congress

'Rethinking healthcare systems in Europe: how to incorporate the patients perspective' organised by the Permanent Representation of Denmark to the European Union

1st European Atopic Eczema Awareness Day is launched

"We created the Swedish patient organization for people living with atopic eczema – Atopikerna – the same year as EFA launched the first Atopic Eczema Awareness Day. Our mission is to convey the needs of people living with atopic eczema. Patients see their doctor approximately once a year, so they need to practice self-care. We strive to empower this enduring group of people."

Sofie Vrang, Atopikerna Chairwoman

#AtopicEczemaDay

<http://www.efanet.org/resources/library/3405-european-atopic-eczema-day>

EFA deeply thanks the 13 volunteer patients involved in the photo project, for their courage facing atopic eczema every day and their generosity sharing their daily 'atopical lives' to show other patients that they are not alone.

EFA's first ever organized European day focused on atopic eczema and took place on September 14th 2018 during the European Academy of Dermatology and Venerology (EADV) Congress in Paris. The event served to build and launch the coordinated patient voice on atopic eczema in Europe, in collaboration with the Global Skin organisation, who launched a World Day at the same time.

'Atopical Lives' a photo exhibition featuring the life and portraying the people behind atopic eczema

Following our essence, we shed light into the real burden of atopic eczema with an impactful series of testimonials developed by photojournalist Lurdes R. Basolí, who travelled Europe to meet 13 patients



EFA Atopical Lives exhibition was formed of 35 pictures portraying daily life, itching, treatment, love, family and work with atopic eczema from the youngest to the adult age.

from Czech Republic, France, Italy, the Netherlands and Spain. Half of them took part in the photo tour organized in Paris on September 13th, an emotional experience for all participants in the visit, including the EFA team.

Media and partners echoed the first edition of the atopic eczema day

EFA press and social media work ahead of the action day resulted in four European and several national media reporting. The atopic eczema report had a special influence in Spain with 38 national media hits, following a pilot public relations project led by EFA and our Spanish Members AEPNAA and FENAER. We also welcomed specialized journalists during EADV to a Press Briefing on the results of the Quality of Life survey and the impressions of the patients. We warmly thank Bernd Arents from VMCE and Marjolaine Hering from Association Française de l'Eczéma for sharing their experiences with the journalists.

We also thank our Members for their mobilization to draw attention to atopic eczema at national level through the use of an atopic eczema filter and EFA coordinated messages. Our collective voice got the attention and support of individual personalities, partners and public authorities, such as the European Medicines Agency and the European Chemicals Agency.

Active Patient Access Care – Do they?

"My test results were misinterpreted for so many years... spirometry was performed and there was increased expiratory resistance but no one determined the disorder as COPD or asthma."

COPD patient from Poland

#ShowLeadership
<http://www.efanet.org/campaigns/ShowLeadership>



Despite the great efforts done in the last decades by patient organisations and patient advocates, inequalities and access barriers may be more persistent than we think among European patients needing allergy and airways diseases care. While research is progressing and new diagnostic and treatment opportunities and self-management solutions are becoming available to patients, we do not know if and how those are integrated into the different European healthcare systems. Are European countries adopting new prevention and care measures for people with respiratory diseases? Does the current available disease-specific support respond to the needs and interests of the patients?

Active Patients Access Care !
7 countries
774 asthma and COPD patients
6 languages
4 patient-driven topics

To answer all these questions, in 2018 EFA launched a survey for asthma and COPD patients to assess the level of patients' access to Diagnosis, Care, Prevention, and Patient Empowerment. Together with EFA Members, we translated the questionnaire into six languages and interviewed 774 patients in Finland, France, Germany, Italy, Poland, Spain and United Kingdom, 387 asthma, 387 COPD. The results will be available in February 2019 and will be key to #ShowLeadership, an EFA European campaign to highlight patients' emotions, care choices and priorities and to request political and policy action in Europe.

Building allergies and airways diseases patients capacity in Europe

"The Capacity Building webinars were well organized among experts who provided useful hints and spaces dedicated to sharing experiences among the attendees. EFA's Meet & Greet gave us the great opportunity to learn more on how to make our voice heard on the current air quality, chemicals and reimbursement policies and also through practical activities, how to make more effective our message with MEPs in the upcoming EP elections."

Marcia Podestà, Food Allergy Italia

#EFAEvent
<http://www.efanet.org/inform/expert-patient-network>

Since 2014 EFA runs a Capacity Building Program to transfer knowledge between members facing limited resources, information and tools. In 2018 for the first time we launched 10 **online sessions** (webinars), allowing more EFA Members and their members to participate. They attended presentations from expert external speakers in the fields of governance, fundraising, membership, project management, communication and advocacy and contributed by posting their experiences at national level.

With the aim of facilitating the **establishment of patients associations** in countries where patients groups are less represented, we also organised a meeting with a group of Romanian patients willing to establish a respiratory diseases and allergy patients' organisation. We discussed about the situation of patients, the perception of our disease areas in Romania and also about how to build and run a patient organization successfully.



EFA travelled to Brasov (Romania) to meet with 11 patient leaders interested in building a patient organisation.

Local organizations such as the Romanian Tuberculosis Patients Association, the European Academy of Allergy and Clinical Immunology (EAACI) and professional journalists also brought their experiences to the meeting. In 2019 we will activate a similar process in Georgia.

Delayed to January 2019, we organised our 9th annual **'Meet and Greet the EU Training'** in Brussels, an effective way of familiarising EFA members with the European Union. Through meetings with EU officials, our members had the possibility to increase the involvement of patients with allergy and airways diseases in EU policymaking.

During the training, participants from six EFA Members from Austria, Italy, the Netherlands, and Spain, got an overview of the most important ongoing policy discussions at the EU level. Topics were air quality, chemicals and access to healthcare. Our guests met with a total of 11 Members of the European Parliament. In a practical training session, they learnt how to maximize their advocacy and policy influence through a mix of scientific evidence, patient stories and speech techniques. The meeting met participants' expectations at 85%.

Channelling our knowledge to EU research projects

#Cure_asthma
www.cureasthma.eu



For the majority of asthma patients in Europe it is possible to achieve better life through existing treatments (if accessible), but their dream to get rid of asthma is not yet there. The partners of the EU-funded research project CURE including EFA are studying a hypothetical solution to prevent asthma.

Launched in 2017, the project is analysing the possibility of a virus-based therapy (bacteriophages) to reduce the chronic inflammation of the airways. In 2018, EFA contributed to the project with internal and external communication materials, publishing through social networks and increasing visibility of the consortium work.



The typical structure of a bacteriophage.

#myaircoach
<http://myaircoach.eu/>



Sensors and trackers represent the core of latest innovations to hit consumer health, but it is not just about counting steps and heart rate. MyAirCoach is a project funded by the EU Programme Horizon 2020 that has developed a system for the self-management of asthma, made of smart sensor-based devices and online platforms and mobile app. It monitors the inhalation technique, as well as several environmental factors at the patients' home, such as NO₂, SO₂, PM levels, temperature, humidity and pressure. The data is then accessible to patients and their healthcare professionals through a mobile app, which includes other tools and information that empower the patients to self-manage their disease.

In 2018, myAirCoach was evaluated by asthma patients from the UK and the Netherlands. Last improvements were

made possible thanks to the contribution of 22 members of the Advisory Patient Forum (coordinated by EFA) who tested the myaircoach components before these were made available to a wider patient audience.

Although the analysis of the evaluation study of myaircoach is not finalised yet, the preliminary results show that the system leads to an improvement of asthma control, and a reduction in severe asthma exacerbations. It also shows improvements in quality of life with. The technology was well accepted by patients, it only takes a one hour training sessions and about half an hour telephone support per patient, and it seems to be cost-effective.

Our Governance

"As EFA Board member I am strongly committed to further building EFA's capabilities and resources, so that it becomes even more influential organization within the EU. I believe in collaboration, teamwork and a strong and effective voice from patients suffering from allergies and airways diseases."

Ilkka Repo, Finnish allergy, skin and asthma federation

#EFAEvent

<http://www.efanet.org/about-efa/organisation>



EFA Member Delegates, Board and Staff during 2018 Annual General Meeting in Lisbon.

The Annual General Meeting (AGM) is the most important gathering of allergy, and airways diseases' patient leaders who share EFA goals. The 2018 AGM brought together 38 leaders from 18 countries to decide on governance and to share best practices between themselves and throughout EFA thematic working group sessions. The AGM scrutinised and approved EFA's work plan and budget for next year, as well as the annual accounts and report from 2017. The event was cordially hosted in Lisbon by our Portuguese members, APA and RESPIRA, who ensured the participation of the leader of the Portuguese national programme on respiratory diseases.

Guests from EFA's medical society partners, the primary care (the IPCRG), allergologists (the EAACI) and pulmonologists (the ERS), as well as the European Alliance for Personalised Medicine and experts on ethics and digital care joined us in the meeting to share with us the latest advances in personalised care.

We welcomed new leadership and Members

The AGM welcomed a new Board Member, Ilkka Repo, CEO of the Finnish Allergy, Skin and Asthma Federation, who brings with him economic, strategic and leadership background. We send special thanks to Carlos Nunes from APA, who served as Secretary of Board from 2016-2018.

EFA welcomed one new member to our 42 associations, the French Eczema Association, focused on raising awareness and patient education on atopic eczema, expanding our actions to represent the needs of atopic eczema patients, special category in allergy. We also received two applications from recently created associations: Turkish COPD Association and Allergienet from Belgium. Since they do not fully meet our membership criteria yet, they attended our AGM as observers.

New EFA policies

In 2018, we adopted a **Memorandum of Understanding** with EAACI establishing strong and long-term partnership with this organization with whom we share high level information and objectives and work very closely in joint projects like the European Parliament Interest Group on Allergy and Asthma.

We also adopted a **new privacy and cookies policy** compliant with the General Data Protection Regulation which safeguards the privacy of those that sign up to support EFA, especially when sensitive information is required.

We launched a membership survey in 2018 that was completed by 1 out of 3 Members. The survey will help establishing evidence on who exactly we represent; the disease focus on our Members, their capacity and representativeness. We will then update our Membership Strategy.

Treasurer's report



"As a charity, we are not collecting money but dedicating it into the necessary activities to advocate change for all people with allergy and airways diseases."

Hubert Nettel, EFA Treasurer

I am pleased to say that our year ended with a surplus of 906 Euro, in line with the result forecasted in our budget for the year 2018.

As often is the case, the year went fast and due to a delayed start, our Active Patients Access Care survey got completed in 2018, with the results delivered in early 2019. To cover the planned cost, we deferred the funds to 2019, and we did the same to run our 2018 Meet and Greet the EU training in January 2019, an activity from our Capacity Building Project.

As a charity, we are not collecting money but dedicating it into the necessary activities to advocate change for all people with allergy and airways diseases.

In addition to our quarterly finance reports discussed at EFA board meetings, we started to present the overall balance sheet in all board meetings to strengthen the oversight of our leadership.

My goal as treasurer is to help EFA to plan and budget for the following year as early as possible, and close the accounts of the previous year early. This will also help our corporate funders planning.

Our income remained stable, enabling continuity, projects delivered as planned and overall trust. This however does not mean it is easy to get. In fact, it is tight. I therefore thank the funders sincerely as well as EFA Office for excellent management. It is my fourth year now as treasurer and a privilege to help the EFA community in the necessary financial affairs. I can see the result. This boat is worth sailing, join us to load it!

Auditor's statement

Independent practitioner's review report on the financial statements of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) for the year ended 31 December 2018.

Report on the Financial Statements

We have reviewed the financial statements of EFA, which a balance sheet total of 744.134,46 EUR and income statement with a profit of 906,37 EUR.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these statements in accordance with the financial-reporting framework applicable in Belgium, and for such internal control as management determines is necessary to enable the preparation of the financial statements that are free from material misstatement, whether due to fraud or error.

Practitioner's Responsibility

Our responsibility is to express a conclusion on the financial statements. We conducted our review in accordance with International Standard on Review Engagements (ISRE) 2400 (Revised),

Engagements to Review Historical Financial Statements. ISRE 2400 (Revised) requires us to conclude whether anything has come to our attention that causes us to believe that the financial statements, taken as a whole, are not prepared in all material respects in accordance with the applicable financial reporting framework. This Standard also requires us to comply with relevant ethical requirements.

A review of financial statements in accordance with ISRE 2400 (Revised) is a limited assurance engagement. The practitioner performs procedures, primarily consisting of making inquiries of management and others within the entity, as appropriate, and applying analytical procedures, and evaluates the evidence obtained.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with International Standards on Auditing. Accordingly, we do not express an audit opinion on these financial statements.

Conclusion

Based on our review, nothing has come to our attention that causes us to believe that these financial statements do not present fairly, in all material respects, the financial position of the European Federation of Allergy and Airways Diseases Patients' Associations as at December 31, 2018, and the results of its operations for the

year then ended, in accordance with the financial-reporting framework applicable in Belgium.

Report on Other Legal and Regulatory Requirements

Without prejudice to certain formal aspects of minor importance, the accounting records are maintained in accordance with the legal and regulatory requirements applicable in Belgium.

EFA is registered as Not-for-Profit Organisation in Sweden. EFA is still currently working on its full registration in Belgium and ensuring compliance with the law and regulations. Based on our assessment there are no effects on the financial statements as stated above. There are no other transactions undertaken or decisions taken in breach of the by-laws or of the Law of 27 June 1921 on non-profit organisations, international non-profit organisations and foundations that we have to report to you.

Londerzeel, February 18, 2019
Jean Bernard PIEULI-TAKOU
Registered auditor

Financial statements

"Based on our review, nothing has come to our attention that causes us to believe that these financial statements do not present fairly, in all material respects, the financial position of the European Federation of Allergy and Airways Diseases Patients' Associations as at December 31, 2018, and the results of its operations for the year then ended, in accordance with the financial-reporting framework applicable in Belgium."

Jean Bernard Pieuli-Takou
Registered auditor

ASSETS	2018	2017
Intangible assets	0	0
Restructuring costs	22,177	22,177
Depreciation of restructuring costs	-22,177	-22,177
Furniture	1,740	3,429
Office Appliances	17,778	17,778
Depreciation of office appliances	-16,038	-14,349
Debtors	205,971	163,826
Liquidities	502,255	802,541
Bank Account 0038/4174-7	201,470	501,752
Bank Account 5912/7917-1	250,341	250,344
Handelsbanken 41 402 669	50,445	50,445
Deferred charges and accrued income	34,168	5,111
Deferred Charges	4,050	5,111
Accrued Income	30,118	0
TOTAL ASSETS	744,134	974,907

LIABILITIES	2018	2017
Reserve	346,751	345,844
Reserve last year	95,844	93,510
Social reserve	140,000	140,000
Organisation reserve	110,000	110,000
Excess of income overw expenditure from current year	906	-2,334
Debts	397,384	629,063
Creditors	121,011	91,232
VAT payable on EU deliveries	31,584	38,684
Taxes on salary	0	-667
Social Security	8,162	-15,127
Salaries Employees		
Other social debts		
Received grants for next year (regularisation EU projects)	235,942	484,687
Received fees for next year	685	
Charges postponed to next year		
TOTAL LIABILITIES	744,134	974,907

Income and expenditure

"I am pleased to say that our year ended with a surplus of 906 Euro, in line with the result forecasted in our budget for the year 2018."

Hubert Nettel, EFA Treasurer

INCOME	2018	2017
Operating Programme	270,000	335,000
Grants	270,000	335,000
Membership Fees	14,500	15,000
Projects grants		
EFA Projects	690,546	518,000
Severely Asthma	54,000	0
Interest Group EP	23,334	30,000
Capacity Building	60,500	33,000
COPD	0	103,000
Atopic Eczema	268,000	352,000
Atopic Eczema Awareness Day	130,000	0
Access Survey	154,712	0
EU Projects	53,051	37,626
MyAirCoach	37,272	30,784
CURE	15,778	6,842
Income Previous year	1,531	9,843
Deferred Income 2017	20,800	0
Other income	5,999	9,621
TOTAL INCOME	1,056,427	925,089

EXPENDITURE	2018	2017
Operating Programme	338,706	387,438
Staff	173,902	112,735
Governance	76,593	95,411
Office	52,279	52,587
Equipment depreciation and Maintenance	1,689	9,621
IT Support	2,570	0
Financial Management	0	6,413
Financial Charges	737	1,285
Accountant	15,299	14,224
Audit	2,420	9,680
Membership Fees	1,600	1,600
Activities	57,557	83,468
Board Mission Costs	14,116	18,035
Staff Mission Costs	4,095	9,398
Working Groups & Alignments Meetings	0	224
AGM & Network Meetings	28,530	40,095
Communications	10,816	15,716
Fundraising	30,653	95,824
Project programme	714,555	527,171
EFA Projects	672,384	501,515
Severely Asthma	60,904	0
Capacity Building Project	50,629	33,107
COPD Project	0	99,978
Interest Group EP Asthma	37,743	21,846
Atopic Eczema	235,019	346,584
Atopic Eczema Aarness Day	132,907	0
Access Survey	155,182	0
EU Projects	42,171	25,656
MyAirCoach	29,548	20,182
CURE	12,623	5,474
Other	2,260	8,146
Other Regularisation	0	6,650
Cost Regarding Previous Years	2,260	1,496
TOTAL EXPENDITURE	1,055,520	922,755
RESULT OF THE YEAR	906	2,334

Transparency and acknowledgements

"Thanks to our sustainable funding partners and DG Research and Innovation for supporting our work."

Mikaela Odemyr, EFA President

EFA PROJECT PROGRAMME

Severely, ASTHMA!

Chiesi	€ 10,000
GSK	€ 10,000
Novartis	€ 10,000
Regeneron	€ 12,000
Sanofi Genzyme	€ 12,000

Capacity Building**

Boehringer Ingelheim	€ 30,000
Novartis	€ 30,500

European Parliament Interest Group on Allergy and Asthma

Novartis	€ 11,667
Stallergenes	€ 11,667

European Atopic Eczema Awareness Day

Regeneron	€ 65,000
Sanofi Genzyme	€ 65,000

Active Patients Access Care survey***

Chiesi	€ 38,878
GSK	€ 37,878
AstraZeneca	€ 77,956

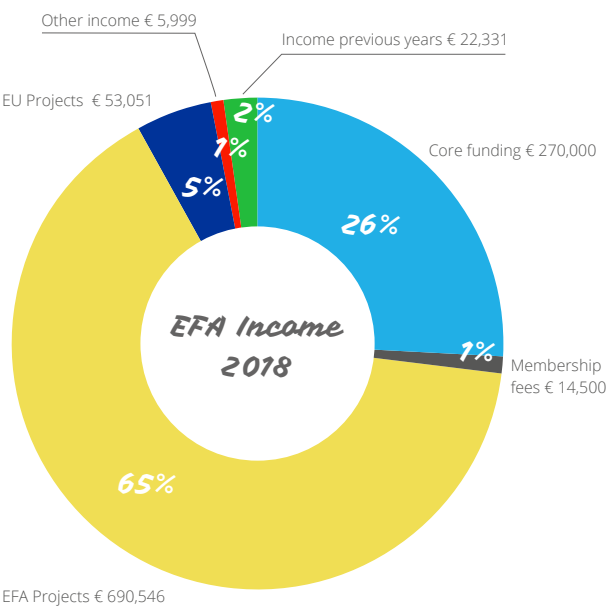
*Sanofi Genzyme partnership ended November 2018 and is been renewed.
**4,500 EUR from Capacity Building (Novartis) moved to 2019 to cover Meet&Greet expenses.
***88,488 EUR from Access Survey moved to 2019 to cover project activities.

OPERATING PROGRAMME

Grants

Astra Zeneca	€ 30,000
Boehringer Ingelheim	€ 30,000
Chiesi	€ 30,000
GSK	€ 30,000
Novartis	€ 30,000
Pfizer	€ 30,000
Regeneron	€ 30,000
Sanofi Genzyme*	-
SigAir Handling	€ 30,000
Stallergenes	€ 30,000

Membership fees € 14,500



Office and thank you



Susanna Palkonen
EFA Director



Giuseppe de Carlo
Director of Operations and Projects



Isabel Proaño Gómez
Director of Policy and Communications



Panagiotis Chaslaridis
Policy Officer



Sofia Romagosa
Junior Projects and Patient Engagement Officer



Maximilian Kunisch
Communications and Policy Assistant



Antje-Henriette Fink-Wagner
Director of Corporate Relations

Thank you

EFA thanks our **volunteer expert patients and Members** who unstintingly contribute through EFA's advocacy or as volunteers to make Europe a place where allergy, asthma and COPD patients live uncompromised lives, have the right and access to best quality care, participate in their care and to have a safe environment. Especially to the ones that actively participated in EFA Projects:

Quality of Life Atopic Eczema Survey: Česká Iniciativa Pro Astma, Astma-Allergi Forbundet, Allergia-, Iho- ja astmaliitto, Association Française de l'Eczéma, Deutscher Allergie- und Asthmabund, Vereniging voor Mensen met Constitutioneel Eczeem, Asociación Española de Personas con Alergia a Alimentos y Látex, Federación Nacional

de Asociaciones de Enfermedades Respiratorias, Astma och Allergi Förbundet, and Allergy UK.

Severely, Asthma!: Asthma UK, Federasma e Allergie Onlus, Longfonds, Asthma Society of Ireland, and Astma och Allergi Förbundet.

Active Patients Access Care: Hengitysliitto, Association Asthme et Allergies, Fédération Française des Associations et Amicales de malades Insuffisants ou handicapés Respiratoires, Federasma e Allergie Onlus, Polska Federacja Stowarzyszeń Chorych na Astmę i POChP, and Federación Nacional de Asociaciones de Enfermedades Respiratorias.

Special thanks to the **EFA Office**, and to Ms Roberta Savli for her contribution to the development of EFA's policy and strategy as a team member from 2012-2018. Thanks also to Ms Nolwenn Coutel-Darieu and Caroline Heilpern who worked at EFA in 2018 as Communications Assistant and Health Policy and Engagement Officer respectively.

EFA thanks sincerely our **sustainable funding partners** who have made our work possible.

EFA thanks the work of the many **organisations** that embrace our mission and mission and that collaborate with us on a daily basis to defend the interests of allergy, asthma and COPD patients in Europe.



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