

European Centre For Allergy Research Foundation (ECARF)

## Activity Report 2015

In 2015, we came a bit closer to reaching the goal of our foundation: to increase the quality of life for allergy sufferers. We enabled scientists in important allergological fields to continue their research. To improve the everyday lives of allergy sufferers and their families, we defined several key objectives for our foundation activity, developed and carried out public awareness projects, provided more guidance to consumers and travellers with the ECARF Seal for Allergy Friendliness, and provided specific support for optimising patient care.

The key areas of our activities are as follows:

### Research and support

ECARF scientists took the opportunity again to present their research results at major global conferences in 2015. Our annual distinction for young doctors, the ADF/ECARF Award, was granted at the 42nd Annual ADF meeting (Arbeitsgemeinschaft Dermatologische Forschung) in Ulm, Germany, for foundational work on anaphylaxis.

In terms of top global research, many excellent scientific publications in leading medical journals were made possible with the help of the foundation. We were also involved in basic work, supervising students writing their final papers on allergy-related subjects.

We broke new ground in terms of application studies on products that play an important role in the everyday lives of allergy sufferers. For the first time, ECARF scientists provided clinical proof that air purifiers have real health benefits for people with pollen allergies, using grass pollen – which is widely dispersed – as the example in our study. The study was developed by ECARF experts and conducted in collaboration with highly qualified network partners. The test itself was carried out in a mobile pollen chamber, the only one of its kind in the world, which enables the use of brand new technical methods for scientific work with airborne allergens.

### Projects and initiatives

Prevention is one of our key areas of activity. We therefore moved forward with the project “Do you Have Allergies Too?” for kindergartens and primary schools. Through

eLearning modules, we provided information to childcare workers and teachers across Germany about allergies in young children. At the same time, children were addressed in an easy and playful way with a picture book. 'Enno and the Itch Ghosts' is the pro-integration story of a kindergartener with atopic eczema and a food allergy. Employees went back to their kindergartens in Berlin and read aloud from the book with great success. Many kindergartens have ordered the free book from us for their pedagogical work.

Seniors are a target group that we have begun to address, as they are largely neglected in both allergy prevention and research. The elderly suffer from severe itching of the skin. The nursing home staff and the seniors themselves do not always possess sufficient knowledge in proper skin care for the elderly. With the support of the Poesch Foundation, we were able to implement a two-phase project.

In the first phase, we established a special pruritus clinic for seniors at Allergie-Centrum-Charité, Charité-Universitätsmedizin Berlin. In the second phase, our pruritus experts conducted training sessions in selected retirement homes for



residents and nursing staff in order to provide them with information about the special requirements for skin care in the elderly. The feedback was so positive that we have planned to continue the project in 2016.

The aim of our photo project for Allergie-Centrum-Charité was to educate while emphasising well-being. The consultation room of the allergy clinic, the patient waiting room and the

hallways of the clinic were decorated with large-scale photographs. All of the images are allergy related, showing grasses, ears of grain, the flowers of fruit trees during the pollen season, and the like. The photographs were supplied to the Foundation free of charge by a volunteer photographer and received much praise and appreciation from patients and the clinic staff.

## Communication

In the last year, ECARF got closer than ever to people with allergies and journalists specialised in healthcare. We spoke about allergies to a wide range of target groups such as kindergartens and primary schools, urticaria patients, healthcare policymakers and the general public through many communication platforms.

- Events

A discussion panel was held on the occasion of Berliner Stiftungswoche (Berlin Foundation Week) as a cooperation between ECARF and the Sarah Wiener Foundation. The topic was healthy food in kindergartens and primary schools for children with and without allergies. The event allowed us to increase awareness of options for healthy eating that are allergy friendly at the same time. Nutrition and health experts, parents, and childcare workers with routine experience participated in the discussion.

Further events and initiatives in cooperation with network partners:

- Project of Aktionsforum Allergologie (AFA - Allergology Action Forum) for a prevention program throughout all of Germany and a comprehensive care concept for allergy sufferers. Six professional allergological federations and associations have joined forces in the AFA
- Joint appeal with AeDA (German Medical Association of Allergologists), Allergie-Zentrum Wiesbaden and MeinAllergiePortal against the plan of the joint federal commission 'Division of Medicines' to negotiate discount contracts for adrenalin autoinjectors and to introduce an aut idem regulation
- Support of the second World Urticaria Day, providing an opportunity for patients to find out whether their urticaria is well controlled, and to take the online Urticaria Control Test (UCT), developed by general practitioners and allergologists.
- Participation in the main event of German Lung Day in Berlin. The public received information about the entire spectrum of respiratory and skin allergies through presentations and health checks.
- On the open house day of the Federal Ministry of Health, our foundation took the special opportunity together with Deutsche Gesellschaft für Allergologie und Immunologie (DGAKI - German Society for Allergology and Immunology) to provide information about allergies, the most widespread chronic disease. Prof Torsten Zuberbier, Chairman of the ECARF Foundation, was at the stand personally giving federal health minister Herrmann Gröhe an overview of the current status of allergy research.

2015 was the year ECARF became active in political lobbying. Themes and goals were defined, a strategy was developed, target groups and potential partners were identified. The initial communication plan included the preparation of an ECARF newsletter aimed at decision makers and opinion leaders in healthcare policy.

Raising awareness among the general public on the subject of food allergies was also a reason for ECARF to begin a cooperation with peb Plattform Ernährung und Bewegung e.V. (Food and Movement Platform) for 2016. peb is a public federation with over 100 members from the public sector, science, economy, sports, the healthcare sector and civil society. They share the mission of promoting a balanced diet and regular, sufficient exercise as a significant part of a healthy lifestyle for children and teenagers.

- Networking

Since 2015, ECARF has taken on a stronger role within the German foundation landscape. We express our concerns about allergies from a medical and societal standpoint, referring to issues such as the gaps in the healthcare system and inadequate therapies.

We kicked off our information campaign aimed at other foundations at the Health Foundations Forum of the Association of German Foundations. This was followed by appearances at Deutscher Stiftungstag (German Foundation Day) in Karlsruhe and the Central German Fundraising Day in Jena.

- Public relations

Communication with media representatives reached its first peak in the spring at the start of the pollen season. At the annual conference of Stiftung Deutscher Polleninformationsdienst (PID - German Pollen Information Service Foundation), organised and moderated by ECARF, the Foundation defined the allergy-related topics for journalists for the months to come.

A new smartphone app from TK (Techniker Krankenkasse) called 'Husteblume' was also presented at the conference. The app supports pollen allergy sufferers with features such as an individualised pollen forecast. PID and ECARF contributed to the content of the app.

ECARF was actively involved in opinion making on allergy-related issues throughout the entire year. For the first anniversary of the EU allergen labelling regulation for non-packaged food, the Foundation conducted a quick survey among breakfast guests at a hotel. The results: 86 per cent considered allergen labelling useful, even if 79 per cent of those surveyed did not have any allergies. Overall, allergen labelling on site was not visible enough.

In order to increase the visibility of the ECARF Seal of Quality in daily newspapers, we entered into several media cooperations during the year, documented on the web

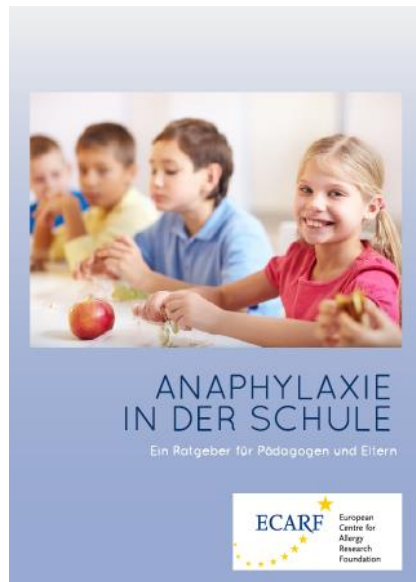
portals ‘Allergies & Airways’ and ‘Air & Lungs’, where new therapies are presented or explained, such as how a mobile pollen chamber works.

Interviews are often the preferred way of sharing knowledge through journalism to the general public – for example, the Foundation director speaking with a news agency about current issues, or an extensive background interview with the prizewinner of the ADF/ECARF Award about advances in the prevention and treatment of anaphylaxis.

- Print and web communication

We developed a new written series for parents and teachers about children with allergies. It started off with the brochures ‘Anaphylaxis at School’ and ‘Asthma at School’, which gave parents and teachers helpful advice and received very positive feedback. The brochures are free of charge and available to the public for download.

Social media was one of the indispensable communication channels for our foundation work, even more so than in previous years. We made an effort this year to revise the strategy for our presence on Facebook and Twitter and to further develop it according to plan, with the goal of an active community in which users can not only learn more about current Foundation projects but also express themselves. We had a significant increase in followers in 2015 compared to the previous year.



The Foundation website, [ecarf.org](http://ecarf.org), is aimed at allergy sufferers, people interested in the work of the Foundation and who may wish to support us on a volunteer basis, and journalists. Over the course of the year, a new section was added to the website on ‘Healthy Living’. It offers many practical tips in an engaging way for everyday life as an allergy sufferer. In addition to the tips, there are also articles and allergy-friendly recipes from ‘Kochtrotz’, a well-known food blog also popular among people without food allergies.

A photo database of allergenic plants was also set up for journalists on the website in the ‘Latest News’ section. It focuses on plants included in the pollen calendar of PID (German Pollen Information Service Foundation). Alders, ashes, birches, grasses, cereals and many other plants are shown in various growth phases, with an emphasis on images of the plants during the respective pollen season that affects allergy sufferers the most.



We have compiled photo documentation for photojournalists and the general public – for example, depicting a patch test or a scratch test step by step. We presented an in-depth photo series on the collection and evaluation of data for a pollen forecast. All photographs were taken by volunteer photographers of the Foundation.

### **ECARF Seal for Allergy Friendliness**

A key part of the public relations work of the ECARF Foundation is the granting of a seal for allergy-friendly products and services. The seal helps allergy sufferers navigate through everyday life. For example, 13 dining halls and cafeterias of the Göttingen student union were certified with the ECARF Seal for Allergy Friendliness. A few months later, the Osnabrück student union followed suit with 11 dining halls and cafeterias and a kindergarten kitchen on the campus. Both student unions took comprehensive measures to adapt to the needs of students with allergies according to the ECARF criteria.

In 2015 the number of products and services certified with the ECARF Seal reached 2,000. The demand for certification from goods and service providers increased again compared to the previous year. The visibility of the Seal increased on the certified product itself, with the Seal featured several times on the front of the pack rather than on the back of the pack, as it frequently did in the past.

We also succeeded in expanding the list of certified municipalities. Staatsbad Salzuflen and Oberstdorf in the Allgäu joined the list of allergy friendly municipalities in 2015.

- **Cooperation partners**

We entered into new cooperation agreements for the certification process in order to enhance our support of travellers with allergies. For example, one of the partners is a medium-sized rental agency in northern Germany; another is a healthcare consulting firm in Lisbon specialised in allergy friendliness in Portuguese vacation hotels. The hotel industry in Portugal is very interested in adapting its services to international visitors with allergies.

We acquired a skilled partner for the technical inspection of washing machines for allergy friendliness, VDE Inspection and Certification Institute in Offenbach. Pollen and pet hair on freshly washed clothing can pose a serious risk for allergy sufferers.

Proof that a washing machine can effectively wash out these kinds of residues ensures greater safety and a better quality of life.



### **Donations and fundraising**

As a non-profit foundation, ECARF depends on donations and financial support in order to continue its work. For this reason, a new appeal for donations for selected projects was launched in 2015:

- Games and literature for children with food allergies. We would like to collaborate with graphic designers, doctors and children's authors in developing games and learning materials that teach kids how to deal with allergens and safe foods
- Set up an atopic dermatitis clinic for expectant mothers and young families
- Provide further support to Allergie-Centrum-Charité
- Create information materials about allergies