



Activity Report 2016

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Foreword

Dear colleagues, friends and partners,

Freedom is a wonderful thing. To be able to move about freely and make informed decisions are values that we take almost for granted in our society. For example, many people this past year wanted to know which foods are healthy and wholesome.

People with chronic, severe allergies are not free to choose or act as they please. Their health needs, anxiety and the restrictions imposed by the therapy they are receiving are not temporary decisions aimed at a more environmentally sustainable or healthier life. These people deliberately exclude much from their lives in order to protect themselves – and in order to survive, in some cases.

In 2016, ECARF laid the foundation for a communications initiative that gives people with allergies back some their lost freedom. On our new website, in schools, in retirement homes, within the framework of our political activity, or at our information stand at public events – the ECARF volunteers have made it their goal to transform objective, evidence-based and accessible knowledge into new courage.

It fills me with pride that the outpatient department of the Comprehensive Allergy Center Charité and the allergology research groups were able to plan new projects and continue their work in progress again this past year, thanks to the financial contribution of the ECARF Foundation.

We succeeded in making many changes in 2016 with the support of our donors and partners, for which I express my heartfelt thanks. I hope you enjoy reading this report.

Sincerely,

Prof. Dr. Dr. h. c. Torsten Zuberbier

Chairman of the Foundation

Our mission

Our mission is to ensure that people with allergies receive the best possible guidance and treatment in everyday matters and therapy options. We believe that allergy sufferers should not be alone in assuming responsibility for a life with severe and chronic allergies. We are dedicated to integrating people with severe allergies and dealing responsibly with allergies and allergens.

We are committed at the federal and state level to raising the required awareness of allergies and appealing for long overdue improvements. We provide allergy sufferers and those around them with independent, relevant information. Through our support, the Comprehensive Allergy Center Charité is able to present new findings in allergy research and improve on-site medical care.

Commitment to allergy awareness requires political engagement

The situation of people with allergies can only be improved if the political system provides the right framework conditions. This is why ECARF is committed to raising allergy awareness at the federal and state level.

The goal has not yet been reached

Medical care for allergy patients in particular is suffering under the economic pressure in the healthcare system. As a result, the number of medical practices that invoice for allergy treatment services has decreased by nearly a third over the past several years. Specifically, many general practitioners have stopped providing treatment for allergies.¹ But the number of people with allergies has not decreased.

The political side has seen some major initiatives with the revised food allergen labelling, the EU Nickel Directive, and the Regulation on Therapy Allergens. But the goal has not yet been reached. Apart from healthcare itself, research promotion, environmental policy, family and education policy are key challenges that lie ahead. For example, it has not yet been legally defined which first aid measures a childcare worker is authorised to take in response to an allergy emergency.

The commitment of the ECARF Foundation

The ECARF Foundation communicated with politicians from various parties in 2016 with the objective of advancing and influencing measures at the legislative level.

This included individual discussions and the distribution of a political newsletter. Since the first issue of the ECARF political letter in March 2016, the Foundation has been sending up-to-date information twice yearly to around 1,500 federal and state politicians. Aspects of allergy healthcare, legislation for allergy emergencies, and planting schemes in public spaces were some of the topics covered in 2016.

The political work recently started by the ECARF Foundation is already bearing fruit, as is evident not only from the many positive reactions and the wide interest in our political information. In August 2016, we participated for the second year in a row in the open house day of the German Federal Ministry of Health, educating visitors and providing them information about allergies.

ECARF on tour for our seniors project 'Pruritus in the Elderly'

There has not been much interest so far among researchers in itching and allergies in the elderly. Itching is a problem that comes with aging, affecting no less than 20.3 % of 60 to 70-year-olds². Little research has been done on the causes of this ailment, which are many. They are often difficult to treat and for caregivers to manage. Mature skin is thinner and drier, with a loss of elasticity, and the barrier function against external influences is weaker. Older people can also experience negative interactions with other medications that they are already taking for other primary diseases.

Seniors project goes into the second round

For the elderly, the skin is a particularly important barrier to the environment. Because seniors often come into physical contact with caregivers, their skin should ideally be intact and have healthy protective properties. For these reasons, the ECARF Foundation launched a funded seniors project that continued into its second year in 2016. The aim of the project is to provide better information and treatment options for seniors. The project also builds valuable knowledge for nursing professionals. A seniors clinic for itching (pruritus) was launched at the Comprehensive Allergy Center Charité of Charité – Universitätsmedizin Berlin with the support of ECARF. Many seniors now take the opportunity to learn more about their own conditions and talk to specialists who recognise and understand the personal difficulties caused by aging skin.

On-site assistance – retirement home visit

Our aim is also to develop skills in elderly care. Volunteer medical workers from our foundation conducted training sessions in retirement homes in Berlin on the subject of itching in the elderly. During these sessions, we provided the nursing staff with the latest research findings on problem skin, itching, and allergic reactions. We also held discussions and Q&A sessions that encouraged seniors to engage in self-care and left them feeling more confident.

Presentation of the ADF/ECARF Award 2016

One of the key objectives of the ECARF Foundation is to promote allergy research. Since 2005, ECARF has been awarding a research prize for outstanding work in allergology. The 'ADF/ECARF Award for European Allergy Research', endowed with €5,000, is awarded annually in cooperation with ADF (Arbeitsgemeinschaft Dermatologische Forschung – Society of Dermatological Research). The research projects presented to specialist colleagues at the ADF Annual Meeting are considered for the award. The prize is awarded to the best submission on an allergy-related subject. The winner is selected by an independent, four-member advisory board composed of leading medical experts and chaired by the director of the ECARF Foundation. The prize can also be awarded to more than one person, in which case the prize money is shared.

Study demonstrates how the gut microbiome influences allergies

Thomas Volz received the prize in 2016 for his groundbreaking study on the gut microbiome. Microbiomes describe the composition of microorganisms according to their genes in areas of the human body, for example, the microbiome of the skin, gut or mucosa. Volz and his team of researchers from the Technical University of Munich and Universitäts-Hautklinik Tübingen (University Dermatology Clinic of Tuebingen) investigated whether immune signals of the gut microbiome have an influence on sensitisation to food allergens and the severity of allergic reactions. They confirmed this hypothesis in their study. This was also the key to new perspectives in therapy and prevention, as sensitisation to food allergens could be significantly attenuated through changes to the bacterial colonies in the gut. The research work may be of great significance to the future treatment of patients with food allergies. Foundation chairman Torsten Zuberbier (left) presented the award certificate to Thomas Volz (right) at the ceremony in Vienna on 11 March 2016.

Interview with the researcher

In an interview with ECARF, Volz explained the complex relationships of his research work so that people without medical training could better understand the results of the study. The discussion also generated a great deal of interest among specialised journalists.

Good information is the best protection

There is a high prevalence of allergies in Germany. One in three people claim to have suffered from an allergy at least once in their lifetime.³ For some, an allergy means having to deal with the discomfort of hay fever every year. For others, a sensitised immune system means that their life or health is constantly at risk. According to a representative FORSA survey, 53% of people with allergies find them burdensome or very burdensome.⁴

Unbiased knowledge helps when making important decisions

Given this high prevalence, allergies have moved into the media spotlight in recent years. A Google search for 'allergies' turns up an abundance of tips on how to manage the disease. Unfortunately, this information is not always up to date or unbiased by commercial interests. As a result, allergy sufferers are left confused, and the social tolerance of 'allergies' as a disorder is on the decline.

The objective of the ECARF Foundation is to provide guidance to people with allergies in everyday matters and help them make therapeutic decisions. We believe that independent, scientifically backed, up-to-date information is needed. The ECARF Foundation therefore launched a communications initiative in 2016 with the aim of providing comprehensive, evidence-based and solid background knowledge to people with allergies.

New ECARF information portal on allergies goes live

We developed information leaflets for parents and teachers and went live with a new website in German and English. The main focus of the new website is the information portal, which features the latest facts on specific allergies and symptoms, and tips for daily life. All of the written content meets strict standards in modern healthcare communication and is guaranteed ad-free.

We share the latest research and medical findings via our Facebook page and Twitter on a regular basis in a way that is practical and easy to understand. We have also increased our cooperation with the press. We managed to expand our reach significantly in the past year, which for us is proof that good information is well received.

Knowledge is the best medicine

We believe that good information can protect people because it helps them assess their own risk. If individuals are sufficiently informed about their illness, they can understand their doctor's recommendations, avoid allergens and prevent exposure. They are also aware of their options and how they can benefit their health. This knowledge not only protects them from allergic reactions, but also helps them reduce their anxiety and stay active.

ECARF certifies the first allergy-friendly school

There is a high prevalence of allergies among children and adolescents. A recent study indicated a lifetime prevalence of asthma of 4.7%, hay fever of 10.7%, and atopic dermatitis of as high as 13.2%.⁵ Children and adolescents spend the majority of their day at school, where children with allergies are particularly prone to exposure to health risks. Teachers and parents also face major challenges in dealing allergies. More questions arise when the people involved come from different cultural backgrounds. Is the allergy really an illness that should be taken seriously, about which the school must be informed? There are no allergies in my home country – not that I have heard of at least, so why should it be important in Germany?

Berlin Brandenburg International School is becoming allergy-friendly. The Berlin Brandenburg International School BBIS in Kleinmachnow, Berlin took on the challenge and applied for ECARF certification as an allergy-friendly school. The school teaches around 700 children of various nationalities at the primary and secondary levels. The language of instruction is English. In cooperation with the school, our experts developed a standard procedure for allergy emergencies, clarified legal issues for teachers, tested cleaning devices and products for allergy-friendliness, introduced cleansing lotions for sensitive skin, and inspected all the plants in the school buildings for their allergenic potential.

The school cafeteria, which is operated by an external caterer, also acquired allergy-friendly certification. Students from all forms, teachers and parents participated in separate training sessions led by ECARF employees. The subjects ranged from ‘What do I need to find out before I swap sandwiches?’ to how to include children with severe allergies at a school party. Everyone gained an overall understanding about the significance of allergies and increased their allergy knowledge, while optimal healthcare practices for children with allergies were established.

ECARF talks with students, nurses and teachers

The training sessions led to a commitment on the part of BBIS to communicate publicly about allergies in a series of interviews with ECARF. The school nurse explained how to organise a class trip with students with allergies, and a 17-year-old student described how she handles daily life with multiple food allergies. The interviews were highly appreciated and resonated with many readers, especially on our social media channels.

Sources

1 Biermann, J. et al. 2013. Allergic disorders of the respiratory tract – findings from a large patient sample in the German statutory health insurance system. *Allergo Journal* 22 (6): 366-373.

2 Zeidler, C.2015. Pruritus im Alter: Jeder Fünfte ist betroffen (Pruritus in elderly: causes, prevention and therapy). *MMW-Fortschr. Med* 157 (5).

3 Langen, U.; Schmitz, R.; Stepphuhn, H.2013. Prevalence of allergic diseases in Germany. Results of the German Health Interview and Examination Survey for Adults (DEGS1). In: *Bundesgesundheitsblatt* (56): 698-706.

4 Forsa. Gesellschaft für Sozialforschung und statistische Analysen mbH (Institute for Social Research and Statistical Analysis). 2012. Survey among 1,000 German citizens for Deutsche Dermatologische Gesellschaft (DDG – German Society of Dermatology).

5 Bergmann, K.C.; Heinrich, J.; Niemann, H. 2016. Current status of allergy prevalence in Germany. Position paper of the Environmental Medicine commission of the Robert Koch-institute. *Allergo J Int* 25: 6-10.

ECARF Profile

Founding year: 2003

Legal form: non-profit foundation constituted under civil law; overseen by Deutsche Stiftungszentrum (DSZ – German Centre for Foundations) and member of the Association of German Foundations

Chairman: Prof. Dr. med. Dr. h. c. Torsten Zuberbier

Volunteers: 15 on the Foundation committee, 7 in the branch offices and 5 in project handling/public relations work; 1 position for the voluntary year of social service

European partnerships: 10

First granting of the ECARF Seal: 2006

Financing:

- Private und institutional donations
- Public project promotion
- Proceeds from the wholly owned subsidiary ECARF Institute GmbH, whose income is allocated exclusively to the work of the Foundation. ECARF Institute GmbH provides comprehensive services in allergy-related matters.

Transparency: ECARF is committed to the goals of the Transparent Civil Society Initiative

Holder of the seal of ethics of the German Fundraising Association (DFRV). For details on the sources and applications of our funds, please visit our website.

Bank account for donations: IBAN: DE 8336 0700 5001 9000 4200 BIC: DEUTDE33XXX