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On the 1st European Atopic Eczema Awareness Day

**New patients report uncovers the reality of severe atopic eczema in Europe**

**PARIS, 14/09/2018, EADV Congress** – When people are asked about their lives with a chronic skin disease like atopic eczema, their answers can bounce back like a reality punch, overturning the perception we have about that disease, and the person living with it.

EFA’s new European report *Itching for Life: Quality of Life and costs for people living with severe atopic eczema in Europe* uncovers the reality of atopic eczema, a chronic inflammatory skin disease affecting 3% of adults and 20% of children in Europe, of which 1 in 5 lives with a severe condition. The results of EFA’s report arise from the biggest-ever Quality of Life (QoL) survey, and shake the prevailing vision on the effects atopic eczema has on patients’ lives. (1) (2)

EFA President Mikaela Odemyr said: “Severe atopic eczema patients need support with the utmost urgency. In our survey they express how they cope with large and deep symptoms for long periods, impacting their whole body, life and energy to face life. They reveal how resilient and strong they are to live with severe atopic eczema, but also how lonely and unacknowledged they live through it, dealing with a constant itch and recurring skin damage. On the 1st European Atopic Eczema Awareness Day, launched by EFA and our Members, we call on the medical and scientific community to join forces to better support patients’ with severe atopic eczema in their daily life challenges”.

The report is launched on the 1st European Atopic Eczema Awareness Day to draw attention to the consequences of atopic eczema symptoms that do not give a break. (3) Many patients (23%) do not have an optimistic view on their life with eczema, 45% had serious eczema symptoms at the time of the survey, and despite care, they had almost every day a dry or rough skin (36%), itchy skin (28%), cracked skin (17%) and felt their skin was flaking off (20%). With only 15% of the patients highly satisfied with their current treatment, patients and their families ask for more investment in research to develop better treatments to break the cycles and flare-ups that dominate the lives of patients. (4)

They also ask for more understanding and multidisciplinary care. For 45% of the patients interviewed, their disease influenced their relationships, sexual life and hobbies, in the week before the interview. Their skin made them feel impared at work (38%). What’s more, 1 in 4 patients in the survey declared themselves sometimes unable to face life, especially among those aged 50+ years.

Not only severe atopic eczema is heavy to body and mind, but also to the pocket. On average annually it costs people € 927,12 to access the health care they need. But also a considerable increase on everyday necessities such as personal hygiene (+18%/monthly).

Show your support to atopic eczema patients and use the Facebook Frame available at: [www.facebook.com/EFAPatients](http://www.facebook.com/EFAPatients)

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**Notes to editors:**

1. The 1,189 participants in the “Atopical Lives” study were adults who had received a severe atopic eczema diagnosis, from 9 different European Union countries (Czech Republic = 52, Denmark = 50, France = 180, Germany = 180, Italy = 180, the Netherlands = 150, Spain = 180, Sweden = 37, and United Kingdom = 180). The report is available at [www.efanet.org](http://www.efanet.org) in 9 languages.
2. The survey was conducted according to Quality of Life (QoL) and economic impact survey methods. To measure quality of life and cost in a way that can be compared across countries, we used existing scientifically validated instruments. The emotional consequences atopic eczema has on patients were measured through a new validated tool developed by EFA. The Atopic Eczema Score of Emotional Consequences (AESEC©) takes into consideration items listed in other Quality of Life studies together with aspects frequently discussed by people with atopic eczema in social media. The items were intentionally reworded into positive and negative statements and were then checked by specialists in psychology, research and language. A questionnaire containing 37 items was pre-tested online in 5 EU-countries (n=100) to inform our selection of the most sensitive and reliable statements. The resulting validated AESEC © contains 28 items, based on reliability and inter-item correlation.
3. The European Atopic Eczema Awareness Day takes place on September 14th and it is an initiative launched by EFA for the first time in 2018 to inform, support and mobilise efforts around atopic eczema in Europe, through an online campaign under #AtopicEczemaDay and a social media picture frame (available at [www.facebook.com/EFAPatients](http://www.facebook.com/EFAPatients)) and a photo exhibition called *Atopical Lives* exposed at the EADV Congress in Paris, under #AtopicalLives.
4. All participants in the survey were invited to leave messages around atopic eczema. EFA has taken those with specific recommendations to improve diagnosis, treatment and life with the disease.

**The European Federation of Allergy and Airways Diseases Patients’ Associations** (EFA) is a network of 43 allergy, asthma and COPD patients’ organisations in 25 European countries and it works for European patients with allergy, asthma and chronic obstructive pulmonary disease (COPD) to live uncompromised lives, have the right and access to the best quality care and a safe environment.

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