

Patient-Centered Outcomes in Food Allergy

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Abstract

Purpose of Review Food allergy prevalence is increasing very rapidly, causing a significant disease burden. The threat of severe allergic reactions occurring unexpectedly and in settings that are not equipped to recognize and treat anaphylaxis is a constant source of worry for individuals and families with food allergies. Inadequate knowledge and understanding in the community significantly impairs the overall quality of life of these individuals and families. Additionally, families face challenges in finding and affording appropriate allergen-free foods.

Recent Findings Advancements have been made in understanding the impact of food allergies on patient-centered outcomes such as quality of life and economic impact, and attempts have been made to develop tools to assess patient-centered variables. Innovative national and regional initiatives are helping to spread awareness of the disease condition and to create resources, including access to allergen-free foods.

Summary While there is a growing momentum toward recognition of food allergic disorders as a condition that profoundly impacts activities of daily living, greater effort needs to be expounded to develop validated tools and interventions that can adequately address these issues.

Keywords Food allergy · Quality of life · Patient-centered outcome

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Introduction

Food allergy affects an estimated 8% of children [1], with steadily increasing prevalence [2]. Although food allergy may be outgrown, there is as-of-yet no curative therapy; management therefore involves vigilant avoidance and judicious treatment of accidental allergen ingestion. Anaphylaxis is a real and anxiety-inducing danger, and a diagnosis of food allergy can impair child and caretaker quality of life [3, 4], create a significant burden both at home [5] and in social situations, and lead to unwelcome stigmatization and bullying [6, 7]. Considerable attention in recent years has been directed toward addressing not only the medical diagnosis of food allergy, but also the many psychosocial aspects of this challenging diagnosis. As new potential therapies arise, attention has turned toward a patient-centered approach, working to empower and involve patients, caregivers, and clinicians to improve healthcare decisions and outcomes.

Quality of Life

A significant factor in patient-centered outcomes is the quantification of quality of life (QoL). A diagnosis of food allergy impacts patient and caregiver wellbeing, and numerous recent studies have evaluated the influence of food allergy on home and social life [4–6, 8, 9]. Families of children with food allergy may have to alter their cooking habits, and a recent study by Bollinger and colleagues [5] revealed that 60% of caregivers of children with food allergy require extra time for meal planning. Many parents worry that dietary changes instituted due to food allergy may negatively impact their child's health; up to one in five parents indicated this concern in a large ($n = 1126$) quality of life study [10]. In this same study, caregivers consistently expressed worry about social

constraints or limitation on their children due to food allergy. Children may miss social activities such as camp, birthday parties, sleepovers, and group sports out of fear of accidental exposure. Remarkably, 34% of parents in one study reported an impact of food allergy on school attendance, with one in ten parents choosing to home school due to food allergy [5].

Many facets of the social environment at school concern caregivers of children with food allergy. According to the School Health Policies and Programs Study 2006, 88% of schools enrolled one or more children with food allergy [11], and a 2005 study of 109 school districts in Massachusetts revealed that 24% of systemic food reactions at schools were in children who were not known to have a life-threatening food allergy [8]. Unfortunately, recent studies also revealed that children with food allergy are frequently bullied, with 31.5% of children, and 24.7% of caregivers reporting bullying about food allergy, including threats of food exposure in one study [7], and 80% of students in another study indicated that the source of bullying was from classmates [6]. A longitudinal evaluation suggests that clinicians should discuss bullying at all food allergy visits, a topic which may not often be covered [9].

There is a relative lack of information regarding food allergy disease-related QoL in relation to other childhood diseases. One study surprisingly indicated that children with peanut allergy experience greater anxiety eating away from home, such as at birthday parties and social gatherings, than children with insulin-dependent diabetes [4], though they did feel positive about eating at familiar restaurants and felt safe when carrying epinephrine. Other studies suggest that children with food allergy have better QoL than children with asthma and other diseases, when comparing a general and disease-specific QoL evaluation [12].

Tools to evaluate food allergy QoL have been developed but are limited by disease-specific factors such as challenges in assessment for the following reasons: occurrence primarily in young children who cannot report their own QoL, lack of day to day symptoms, and fairly low mortality rate [13]; food allergy related QoL is rather better captured by the psychological burden placed on patients and caregivers. An excellent review by Greenhawt et al. [14••] details disease-specific QoL tools currently utilized in the USA including the Food Allergy Quality of Life Parental Burden Index (FAQL-PB) [15], the Food Allergy Independence Scale [5], and the Food Allergy Parent Questionnaire [16], as well as European indices such as the well-validated Food Allergy Quality of Life Questionnaires (FAQLQ) for various age groups [17, 18]. Although currently available assessments deliver awareness to providers regarding the psychosocial impact of food allergy on families, newer tools that measure the impact of emerging therapies on QoL are unquestionably needed [14••].

While many studies assess factors affecting patient and caregiver psychosocial concerns, few address methods or interventions to alter or improve QoL. One blinded-randomized

controlled study examined the impact of providing three phone counseling sessions to caregivers of children with food allergy, addressing concerns, goals, barriers, and coping strategies related to their illness via the “self-regulation” technique; parents in the intervention group had significant improvements in many aspects of QoL, including reduction in anxiety and improved confidence in management of their child’s condition [19]. Another study evaluated group workshops in 61 children and their caregivers; parents noted improved competence and decreased perceived burden [20]. In an effort to determine what may benefit families of children with food allergy, a focus group of 36 parents with experience managing food allergy suggested that a comprehensive curriculum could improve stress, access to medication, and quality of life [21].

From a medical perspective, providers often offer oral food challenges (OFCs) to patients thought capable of tolerating a food to which they are deemed allergic. Two recent studies evaluate the effect of OFCs on food allergy-related QoL. Interestingly, Soller and colleagues discerned that OFC significantly improved QoL scores following challenge in all parents regardless of outcome; however, the effect waned by 6 months in those who failed their challenge ($n = 25$) [22]. The finding of OFC improving QoL regardless of outcome was substantiated by a larger study at an academic center [23•]. Prospective studies on OFCs and other factors affecting food allergy related QoL are lacking.

Economic Impact of Food Allergy

The economic impact of food allergies causes significant challenges for individuals with food allergic disorders. Though data on this is scarce, researchers in 2011 reported that the total economic burden of allergic reactions and anaphylaxis caused by food to be an estimated half-billion dollars with ambulatory visits accounting for more than half of the costs [24]. A more recent study focusing on children and the cost per child with a food allergy showed that the overall economic cost of food allergy was estimated at \$24.8 billion annually (\$4184 per year per child). Direct medical costs were \$4.3 billion annually, including clinician visits, emergency department visits, and hospitalizations. Costs incurred by the family totaled \$20.5 billion annually, including lost labor productivity, out-of-pocket, and opportunity costs. Lost labor productivity costs totaled \$0.77 billion annually, accounting for caregiver time off work for medical visits. Out-of-pocket costs were \$5.5 billion annually, with 31% stemming from the cost of special foods. Opportunity costs totaled \$14.2 billion annually, relating to a caregiver needing to leave or change jobs [25••].

IMPACT OF FOOD ALLERGIES ON FOOD BUDGET

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Item	*Price	Substitute	*Price	Price Difference	Percent Increase
Milk 1 gal	\$4.46	Almond Milk 1 gal	\$7.98	\$3.52	79%
Milk 1 gal	\$4.46	Rice Milk 1 gal	\$7.38	\$2.92	65%
Milk 1 gal	\$4.46	Soy Milk 1 gal	\$6.10	\$1.64	37%
Milk 1 gal	\$4.46	Flax Milk 1 gal	\$9.38	\$4.90	110%
Spaghetti	\$1.28	Gluten Free Spaghetti	\$5.28	\$4.00	313%
Egg Noodles 1 lb	\$1.21	Gluten Free Fusilli Pasta	\$6.13	\$4.92	407%
Elbow Macaroni 1 lb	\$1.28	Gluten Free Penne Pasta	\$7.42	\$6.14	480%
Peanut Butter 1 lb W	\$1.82	Sunflower Seed Spread	\$7.49	\$5.67	312%
Flour 1 lb W	\$0.57	Gluten Free Flour	\$6.39	\$5.82	1021%
Bread 1 lb W	\$0.85	Gluten Free Bread	\$5.42	\$4.57	538%
Eggs 1 doz W	\$1.99	Egg Replacer	\$7.09	\$5.10	256%

W=WIC Food Package Item

*All prices were from a local Market in Kansas City, Missouri in 2016.

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Fig. 1 Impact of food allergies on food budget. Evaluating the price difference and percent price increase of commonly allergenic foods (*first column*) compared to corresponding allergen-free “safe” alternatives (*second column*). Courtesy of Food Equality Initiative [39]

The significant economic burden that families with food allergic disorders bear, when compounded by socioeconomic disparities, further worsen access to safe foods for low-income families [26•]. Allergy friendly foods on average cost two to four times more than foods that contain common allergens and gluten (Fig. 1). For example, the average cost of 1 gal of cow’s milk in Kansas City is \$4.46 (2016 data). If an individual needs a milk alternative, such as hemp milk, the cost increases 237% to \$15.04 for 1 gal. In addition, low income food programs such as Supplemental Nutrition Assistance Program (SNAP) or the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and area food pantries are not designed to address the needs of families impacted by food allergies, essentially creating a gap that results in preventable negative health outcomes and a financial burden on the health care funds. In other words, this often leaves families with a choice between hunger and health.

Current Programs

The leading national organization promoting food allergy awareness is Food Allergy Research and Education (FARE), created in 2012 via the merger of the Food Allergy and Anaphylaxis Network (FAAN) and the Food Allergy Initiative (FAI). FAAN, founded in 1991, pioneered food

allergy educational tools and training programs to raise public awareness of food allergy. The FARE (formerly FAAN) Teen Summit, now approaching its 12th year, is a conference for children ages 11–22 and their caregivers, with sessions directed toward specific to concerns faced in middle school through college [27]. FARE features many educational outlets including monthly webinars and training programs. Community outreach events include the FARE walk for food allergies, a multi-community event raising funds for food allergy awareness and research, and the Teal Pumpkin Project, championed by local food allergy group FACET (Food Allergy Community of East Tennessee). The Teal Pumpkin Project encourages Halloween households to display a teal pumpkin in front of the home and to offer non-food items to allow children with food allergies and other food restrictions to enjoy trick or treating. The project astoundingly reached all 50 states and 14 countries last year [28].

Within the past 10 years, significant legislation related to food allergies has also been enacted, due largely in part to advocacy groups. The Food Allergen Labeling and Consumer Protection Act (FALCPA) of 2004 requires plain language description of the eight major food allergens (milk, egg, peanut, tree nut, wheat, soy, fish, cow’s milk) in all food labels, making it vastly easier for parents of children with common food allergens to read food labels appropriately [29]. The Food Allergy and Anaphylaxis Management Act (FAAMA) was signed in January 2011, passed after 5 years

of lobbying and inserted as section 112 of the larger FDA Food Safety Modernization Act (FSMA) [30]. This act required the US Secretary of Health and Human Services to create a voluntary school policy to aid in management of food allergy, and included incentive grants to support public school guidelines. The FAAMA led to collaboration by the Centers for Disease Control, FARE, the National Organization of School Nurses, and other organizations to release the CDC's National Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs in October 2013 [31]. Additionally, while all 50 states have legislation allowing a child to carry an epinephrine auto-injector, the School Access to Emergency Epinephrine Act of 2013 [32] provides states with a financial incentive to carry non student-specific epinephrine auto-injectors. Although laws differ by state, 12 states now have laws mandating that schools carry non-student specific auto-injectors, and 37 states have laws allowing this action (only Hawaii has pending legislature).

Innovative Solutions to Bridge the Gaps

Despite recent advances in the investigation of social and psychological factors affecting food allergy management, significant gaps exist in public awareness of food allergy, in patient access to alternate “safe” foods and to epinephrine, and in the engagement of patients and families in food allergy clinical care and research. Because of its numerous contributions to raising awareness and improving education of food allergies, FARE was awarded the prestigious Eugene Washington Engagement Award from the Patient Centered Outcomes Research Institute (PCORI) in May 2016 for its two-year project entitled, “Empowering Patient Partners and Key Stakeholders to Develop a Patient-Centric Food Allergy Research Program,” designed to build a partnership among patients, researchers, and healthcare providers. Through this project, an advisory board was created to determine and apply the perspective of patients and caregivers to future outreach and education events and clinical trials. With the funding provided by PCORI, FARE hopes to drastically expand multiple components of food allergy care. In regard to public awareness, school programs are in development, and many restaurants are improving food allergy awareness. Five states, New York, NY and St. Paul, MN now have legislation requiring food allergy awareness information and/or training in restaurants, including the display of posters and training programs for restaurant staff [33].

Local and regional initiatives that engage patients and families in clinical care and research include the creation of advisory councils that can provide direction and priorities to centers/programs offering food allergy care services. One example is the Children's Mercy Food Allergy Patient Family Advisory Council (FAPFAC) [34], a local organization

founded by the author during her tenure as the FARE center director. The Council is comprised of eight caregivers, two patient-centered care coordinators, a medical consultant, and a nutrition consultant (both from the Food Allergy Center) and meets on a monthly basis. The mission statement of the FAPFAC is to work in partnership with the Food Allergy Center staff members to advocate on behalf of parents and patients for the best quality of care. The council serves as a resource for parents to further influence policies and procedures, enhance communication, and expand education for patients and families in both inpatient and outpatient settings.

Another exciting initiative is the creation of a Teen Board at the Sean N. Parker Center for Allergy and Asthma Research at Stanford University [35]. The Sean Parker Community Council is a vibrant and active group of over 130 members that serves to bring together families in trials, trial graduates, and local community members to educate, support, and provide vital input to shape food allergy research at the Center. The Community Council has been instrumental in spreading information about food allergy resources to the community through electronic media [36], written communications, and outreach initiatives, and facilitates community-based participation in clinical trials. Additionally, the Patient Outreach Providers are often former trial participants or parents who are available to help current participants by offering advice, support, and coping strategies. The Center recently launched a Teen Board that pairs new trial participants with volunteer teen trial graduates in order to provide peer-to-peer support as they navigate through a study.

Access to epinephrine auto-injectors, while limited, also continues to expand and improve. Due to efforts by FARE and other organizations, 30 states now have laws allowing (but not requiring) public venues referred to as “entities” to stock epinephrine. While laws vary by state, “entities” may include camps, childcare centers, restaurants, campuses, and/or sporting grounds, according to the FARE website [37•]. Epinephrine access in other public places is continually sought; one particular worry expressed by many parents involves air travel, as peanuts are still available as airline snacks. Recent work has been implemented to require airlines to stock epinephrine injectors and to train crew members in the recognition and treatment of anaphylaxis; the Airline Access to Emergency Epinephrine Act (S. 1972) was introduced in the senate in 2015 and remains in pending legislation [38••].

In 2013, a group of mothers in the Kansas City region who had children diagnosed with food allergies and/or celiac disease endeavored to promote the need for food allergy-friendly and gluten-free products for low income families to help ease the economic burden of living with food allergy. While some families qualified for federal nutrition food programs, unfortunately those programs did not allow the purchase of allergy-friendly or gluten-free products. Local area food banks, though willing to help, were unable to guarantee allergen-

free foods secondary to knowledge and manpower limitations. These enterprising mothers banded together in 2014 and created the Food Equality Initiative (FEI), the first organization in the nation to address allergy-friendly foods for individuals of low income, empowered with the mission to improve health and end hunger in low income individuals diagnosed with food allergies and celiac disease through access to food, advocacy, and education [39]. In addition to promoting awareness to local schools, physicians, hospitals, and community organizations, FEI established a medical advisory board consisting of physicians, nurses, and dietitians from area hospitals, to ensure all services are consistent with established best practice standards.

In the spring of 2015, FEI launched the Allergy Friendly and Gluten Free Nutrition Assistance Program and established the nation's first allergy-friendly and gluten-free food pantry. Since opening the pantry, FEI has supported 90 persons from nine counties in and close to the Kansas City Metropolitan area. The population served is diverse with 3% American Indian/Alaska Native, 7% Asian/Pacific Islander, 11% Black, 63% Caucasian, 11% Hispanic, and 5% other/multiracial. The two qualifying criteria that must be met in order to receive FEI services are (1) a medically necessary diet restriction due to celiac disease or other food allergy as diagnosed by an allergist and (2) proof of income at or below 250% of U.S. Poverty Income Guidelines. FEI uses a "Client Choice" model of service to ensure equitable response to ethnic heritage and diverse food palates. The client therefore receives a list of available products and chooses foods they wish to receive rather than receiving a pre-selected bag of products. FEI has additionally been involved in advocacy to modify the federal WIC food packages to include more allergy friendly options, and the organization has received considerable media attention and acclaim for its innovative pilot model and efforts to ensure every participant can eat safe and healthy food [40]. Efforts to improve public awareness and alleviate the burden of anxiety include creation of public resources to educate and empower patients and families, as well as innovations in clinical practice to provide patients and families with accurate, evidence-based information that can help them overcome fears and lead to better quality of life and improved self-efficacy. Examples of public education and awareness efforts include national initiatives such as FARE, Kids with Food Allergies (Asthma and Allergy Foundation of America), Allergy & Asthma Network Mothers of Asthmatics, and regional initiatives such as Centerview Food Allergy Management, Food Allergy Support Group of Greater Kansas City, and Food Allergy: Connect, Support, Thrive of KC, to name a few.

The Proximity Food Challenge is a novel approach using the Health Promotion model to enable practitioners to empower patients with accurate, evidence-based information that can help them overcome fears and lead to better quality of life and

improved self-efficacy. Fear of life-threatening reactions can plague those with food allergies and cause them to have poorer quality of life. One of the most fear-inducing myths is that of anaphylaxis from casual contact (airborne or skin contact) with food allergens, for example having a life-threatening reaction from just being near peanuts and peanut butter. The Proximity Challenge approach was based on scientific evidence from published literature, and recommendations in the 2014 Food Allergy Practice Parameter Update that advised, "Teach patients that ingestion, rather than casual exposure through the skin or close proximity to an allergen, is almost the only route for triggering severe allergic/anaphylactic reactions" [41•]. The proximity food challenge, performed by experienced practitioners in a safe and monitored clinical setting, helps individuals with food allergies feel and know, in a safe and monitored setting, what to expect with similar future exposure in the real world. A successful proximity food challenge allows for heightened self-efficacy and encouragement of positive health behavior by placing the emphasis back on health rather than on the burden of the disease, in alignment with the Health Promotion Model framework [42•].

Future Patient Outcomes Issues

The encouraging results from ongoing clinical trials on desensitization/immunotherapy methods (oral, sublingual, and epicutaneous) in food allergies [43–47] have the exciting potential to greatly improve patient and caregiver anxiety of accidental ingestion [48, 49]. While these interventions will bring unprecedented opportunities to individuals and families, issues such as ensuring long-term adherence to these therapies (e.g., needing to take the maintenance dose on a periodic basis), their influence on quality of life (e.g., being aware of limitations to the quantities of food allergens that can be safely ingested and accommodating life-style changes), economic issues (e.g., cost of these interventions), and health care utilization (e.g., possible increased requirement of epinephrine in case of reactions during up-dosing or following missed doses) will need to be thoughtfully addressed.

Conclusions

A diagnosis of food allergy affects many facets of patient and caregiver quality of life and causes a significant psychological burden for all involved. Fortunately, light is continually being shed on this issue through the development of quality of life assessment tools, the work of grassroots and advocacy groups, and the initiation of recent legislation to hopefully allow for the development of advances in food allergy awareness and education. Additionally, advances in food allergy research

including proximity challenges and ongoing trials of food desensitization will hopefully help ease the burden of anxiety surrounding accidental ingestion of allergenic foods. This is certainly an exciting and progressive time in the field of food allergy as we strive to create validated assessment tools and novel treatments for our patients.

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Compliance with Ethical Standards

Conflict of Interest Chitra Dinakar is a co-investigator in food allergy desensitization, natural history and prevention studies sponsored by the NIH, Allimmune, DBV Technologies, Astellas, AnaptycsBio at the Sean N Parker Center for Allergy and Asthma Research at Stanford University. She was the founder of the Food Allergy Patient Family Advisory Council at Children's Mercy Kansas City and serves on the medical advisory board of the Food Equality Initiative, Kansas City.

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Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

References

Papers of particular interest, published recently, have been highlighted as:

- Of importance
- Of major importance

1. Gupta RS, Springston EE, Warrier MR, Smith B, Kumar R, Pongracic J, et al. The prevalence, severity, and distribution of childhood food allergy in the United States. *Pediatrics*. 2011;128(1):e9–17. doi:10.1542/peds.2011-0204.
2. Sicherer SH, Sampson HA. Food allergy: epidemiology, pathogenesis, diagnosis, and treatment. *J Allergy Clin Immunol*. 2014;133(2):291–307; quiz 8. doi:10.1016/j.jaci.2013.11.020.
3. Walkner M, Warren C, Gupta RS. Quality of life in food allergy patients and their families. *Pediatr Clin N Am*. 2015;62(6):1453–61. doi:10.1016/j.pcl.2015.07.003.
4. Avery NJ, King RM, Knight S, Hourihane JO. Assessment of quality of life in children with peanut allergy. *Pediatric allergy and immunology : official publication of the European Society of Pediatric Allergy and Immunology*. 2003;14(5):378–82.
5. Bollinger ME, Dahlquist LM, Mudd K, Sonntag C, Dillinger L, McKenna K. The impact of food allergy on the daily activities of children and their families. *Annals of allergy, asthma & immunology: official publication of the American College of Allergy, Asthma, & Immunology*. 2006;96(3):415–21. doi:10.1016/S1081-1206(10)60908-8.
6. Lieberman JA, Weiss C, Furlong TJ, Sicherer M, Sicherer SH. Bullying among pediatric patients with food allergy. *Annals of allergy, asthma & immunology: official publication of the American College of Allergy, Asthma, & Immunology*. 2010;105(4):282–6. doi:10.1016/j.anai.2010.07.011.
7. Shemesh E, Annunziato RA, Ambrose MA, Ravid NL, Mullarkey C, Rubes M, et al. Child and parental reports of bullying in a consecutive sample of children with food allergy. *Pediatrics*. 2013;131(1):e10–7. doi:10.1542/peds.2012-1180.
8. McIntyre CL, Sheetz AH, Carroll CR, Young MC. Administration of epinephrine for life-threatening allergic reactions in school settings. *Pediatrics*. 2005;116(5):1134–40. doi:10.1542/peds.2004-1475.
9. Annunziato RA, Rubes M, Ambrose MA, Mullarkey C, Shemesh E, Sicherer SH. Longitudinal evaluation of food allergy-related bullying. *The journal of allergy and clinical immunology In practice*. 2014;2(5):639–41. doi:10.1016/j.jaip.2014.05.001. **An eye-opening study that shows the alarming rate of bullying in children with food allergies (29%), and that over two thirds of children who reported being bullied in the initial survey continue to experience bullying.**
10. Springston EE, Smith B, Shulruff J, Pongracic J, Holl J, Gupta RS. Variations in quality of life among caregivers of food allergic children. *Annals of allergy, asthma & immunology: official publication of the American College of Allergy, Asthma, & Immunology*. 2010;105(4):287–94. doi:10.1016/j.anai.2010.08.003.
11. O'Toole TP, Anderson S, Miller C, Guthrie J. Nutrition services and foods and beverages available at school: results from the school health policies and programs study 2006. *The Journal of school health*. 2007;77(8):500–21. doi:10.1111/j.1746-1561.2007.00232.x.
12. Ravid NL, Annunziato RA, Ambrose MA, Chuang K, Mullarkey C, Sicherer SH, et al. Mental health and quality-of-life concerns related to the burden of food allergy. *Immunol Allergy Clin N Am*. 2012;32(1):83–95. doi:10.1016/j.iac.2011.11.005.
13. Flokstra-de Blok BM, Oude Elberink JN, Vlieg-Boerstra BJ, Duiverman EJ, Dubois AE. Measuring health-related quality of life: fundamental methodological issues. *Clinical and experimental allergy: journal of the British Society for Allergy and Clinical Immunology*. 2009;39(11):1774; author reply 175. doi:10.1111/j.1365-2222.2009.03376.x.
14. Greenhawt M. Food allergy quality of life and living with food allergy. *Curr Opin Allergy Clin Immunol*. 2016;16(3):284–90. doi:10.1097/ACI.0000000000000271. **Excellent overview of the existing quality of life surveys to assess individuals and families with food allergic disorders.**
15. Cohen BL, Noone S, Munoz-Furlong A, Sicherer SH. Development of a questionnaire to measure quality of life in families with a child with food allergy. *J Allergy Clin Immunol*. 2004;114(5):1159–63. doi:10.1016/j.jaci.2004.08.007.
16. Lebovidge JS, Stone KD, Twarog FJ, Raiselis SW, Kalish LA, Bailey EP, et al. Development of a preliminary questionnaire to assess parental response to children's food allergies. *Annals of allergy, asthma & immunology: official publication of the American College of Allergy, Asthma, & Immunology*. 2006;96(3):472–7. doi:10.1016/S1081-1206(10)60916-7.
17. Flokstra-de Blok BM, DunnGalvin A, Vlieg-Boerstra BJ, Oude Elberink JN, Duiverman EJ, Hourihane JO, et al. Development and validation of the self-administered food allergy quality of life questionnaire for adolescents. *J Allergy Clin Immunol*. 2008;122(1):139–44. doi:10.1016/j.jaci.2008.05.008. **44 e1-2**
18. Flokstra-de Blok BM, DunnGalvin A, Vlieg-Boerstra BJ, Oude Elberink JN, Duiverman EJ, Hourihane JO, et al. Development and validation of a self-administered food allergy quality of life questionnaire for children. *Clinical and experimental allergy: journal of the British Society for Allergy and Clinical Immunology*. 2009;39(1):127–37. doi:10.1111/j.1365-2222.2008.03120.x.
19. Baptist AP, Dever SI, Greenhawt MJ, Polmear-Swendris N, McMorris MS, Clark NM. A self-regulation intervention can

- improve quality of life for families with food allergy. *J Allergy Clin Immunol*. 2012;130(1):263–265. doi:10.1016/j.jaci.2012.03.029.
20. LeBovidge JS, Timmons K, Rich C, Rosenstock A, Fowler K, Strauch H, et al. Evaluation of a group intervention for children with food allergy and their parents. *Annals of allergy, asthma & immunology: official publication of the American College of Allergy, Asthma, & Immunology*. 2008;101(2):160–5. doi:10.1016/S1081-1206(10)60204-9.
21. Vargas PA, Sicherer SH, Christie L, Keaveny M, Noone S, Watkins D, et al. Developing a food allergy curriculum for parents. *Pediatric allergy and immunology: official publication of the European Society of Pediatric Allergy and Immunology*. 2011;22(6):575–82. doi:10.1111/j.1399-3038.2011.01152.x.
22. Soller L, Hourihane J, DunnGalvin A. The impact of oral food challenge tests on food allergy health-related quality of life. *Allergy*. 2014;69(9):1255–7. doi:10.1111/all.12442.
23. Franxman TJ, Howe L, Teich E, Greenhawt MJ. Oral food challenge and food allergy quality of life in caregivers of children with food allergy. *The journal of allergy and clinical immunology In practice*. 2015;3(1):50–6. doi:10.1016/j.jaip.2014.06.016. **This study demonstrates that caregiver quality of life improves after oral food challenges regardless of the outcome.**
24. Patel DA, Holdford DA, Edwards E, Carroll NV. Estimating the economic burden of food-induced allergic reactions and anaphylaxis in the United States. *J Allergy Clin Immunol*. 2011;128(1):110–115 e5. doi:10.1016/j.jaci.2011.03.013.
25. Gupta R, Holdford D, Bilaver L, Dyer A, Holl JL, Meltzer D. The economic impact of childhood food allergy in the United States. *JAMA Pediatr*. 2013;167(11):1026–31. doi:10.1001/jamapediatrics.2013.2376. **This study outlines the significant direct medical costs for the US health care system and even larger costs for families with a food-allergic child.**
26. Bilaver LA, Kester KM, Smith BM, Gupta RS (2016) Socioeconomic Disparities in the Economic Impact of Childhood Food Allergy. *Pediatrics* 137(5) doi:10.1542/peds.2015-3678 **This article elegantly highlights the existence of disparities in the economic impact of food allergy.**
27. 12th Annual FARE Teen Summit (2017). Food Allergy Research and Education, Inc., McLean. <https://www.foodallergy.org/teensummit>. Accessed 26 March 2017.
28. Teal Pumpkin Project FAQ (2016). Food Allergy Research and Education, Inc., McLean. <https://www.foodallergy.org/teal-pumpkin-project/faqs#WK-P1mQrly4>. Accessed 26 March 2017.
29. Public Law. (2004) Food Allergen Labeling and Consumer Protection Act. U.S. Food and Drug Administration. <https://www.fda.gov/downloads/Food/GuidanceRegulation/UCM179394.pdf>. Retrieved 26 March 2017.
30. Public Law. (2011) Food Safety Modernization Act. U.S. Food and Drug Administration. <https://www.fda.gov/food/guidanceregulation/fsma/>. Retrieved 26 March 2017 p 3916–23.
31. (2013) Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs. In: CDC (ed). US Department of Health and Human Services, Washington, D.C. Retrieved 03–26-2017.
32. Durbin R (2013) School Access to Emergency Epinephrine Act. Washington, D.C. <https://www.congress.gov/bill/113th-congress/senate-bill/1503>. Accessed 26 March 2017.
33. Emmons J, Hune J, Smith V, Nofs M, Pappageorge J, Jones R et al. (2015) Michigan State Senate. Enrolled Senate Bill No. 730. Lansing, MI. <https://www.legislature.mi.gov/documents/2013-2014/publicact/pdf/2014-PA-0516.pdf>. Accessed 26 March 2017.
34. Advisory Boards (2017) Children's Mercy Hospital, Kansas City, MO. http://www.childrensmc.org/About_Us/About_Childrens_Mercy/Advisory_Boards/. Accessed 26 March 2017.
35. Sean N (2015) Parker Center for Allergy and Asthma Research Launches Teen Board Stanford Medicine, Palo Alto, CA. <http://med.stanford.edu/allergyandasthma/our-community/teen-board-launches.html>. Accessed 26 March 2017.
36. Our Pioneering Research (2017) In: Sean N (ed) Parker Center for Allergy and Asthma Research. Stanford Medicine, Palo Alto, CA. <http://med.stanford.edu/allergyandasthma/research.html>. Accessed April 2017.
37. Public Access to Epinephrine (2017) Food Allergy Research and Education, Inc., McLean, VA. <https://www.foodallergy.org/advocacy/advocacy-priorities/access-to-epinephrine/public-access-to-epinephrine>. Accessed 03-26-2017. **A concise summary detailing state laws regarding epinephrine auto-injector access.**
38. Steven KM (2015) S.1972 - Airline Access to Emergency Epinephrine Act of 2015. Washington, D.C.. **Recently introduced senate act, still in pending legislation with hope of soon passing.**
39. Food Equality Initiative: About Us (2017) Kansas City, MO. <http://foodequalityinitiative.org/about-us-2/>. Accessed 30 March 2017.
40. Press (2017) In: Food Equality Initiative. Food Equality Initiative, Kansas City, Missouri. <http://foodequalityinitiative.org/press/>. Accessed 10 April 2017.
41. Sampson HA, Aceves S, Bock SA, James J, Jones S, Lang D, et al. Food allergy: a practice parameter update-2014. *J Allergy Clin Immunol*. 2014;134(5):1016–25. doi:10.1016/j.jaci.2014.05.013. **e43 The current guidelines created by the joint task force of the American Academy and College of Asthma, Allergy, and Immunology, serving as the Allergy/Immunology community's primary reference.**
42. Dinakar C, Shroba J, Portnoy JM. The transforming power of proximity food challenges. *Annals of allergy, asthma & immunology : official publication of the American College of Allergy, Asthma, & Immunology*. 2016;117(2):135–7. doi:10.1016/j.anai.2016.06.015. **This article describes a novel procedure that gives families a new alternative for evaluating the ability of the child with food allergies to tolerate casual exposure to the suspected trigger in a safe, controlled setting.**
43. Salmivesi S, Korppi M, Makela MJ, Paasilta M. Milk oral immunotherapy is effective in school-aged children. *Acta Paediatr*. 2013;102(2):172–6. doi:10.1111/j.1651-2227.2012.02815.x.
44. Burks AW, Jones SM, Wood RA, Fleischer DM, Sicherer SH, Lindblad RW, et al. Oral immunotherapy for treatment of egg allergy in children. *N Engl J Med*. 2012;367(3):233–43. doi:10.1056/NEJMoal200435.
45. Burks AW, Wood RA, Jones SM, Sicherer SH, Fleischer DM, Scurlock AM, et al. Sublingual immunotherapy for peanut allergy: long-term follow-up of a randomized multicenter trial. *J Allergy Clin Immunol*. 2015;135(5):1240–8. doi:10.1016/j.jaci.2014.12.1917. **e1-3**
46. Jones SM, Sicherer SH, Burks AW, Leung DY, Lindblad RW, Dawson P, et al. Epicutaneous immunotherapy for the treatment of peanut allergy in children and young adults. *J Allergy Clin Immunol*. 2016; doi:10.1016/j.jaci.2016.08.017.
47. Anagnostou K, Islam S, King Y, Foley L, Pasea L, Bond S, et al. Assessing the efficacy of oral immunotherapy for the desensitisation of peanut allergy in children (STOP II): a phase 2 randomised controlled trial. *Lancet*. 2014;383(9925):1297–304. doi:10.1016/S0140-6736(13)62301-6.
48. MacGinnite A. Update on potential therapies for IgE-mediated food allergy. *Current allergy and asthma reports*. 2017;17(1):4. doi:10.1007/s11882-017-0671-8.
49. Pesek RD, Jones SM. Current and emerging therapies for IgE-mediated food allergy. *Current allergy and asthma reports*. 2016;16(4):28. doi:10.1007/s11882-016-0610-0.