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How Advocacy Groups Are Enhancing Food Allergy Care

Dr. Caudle:

Since approximately 32 million Americans are living with a food allergy, more and more advocacy groups are working to advance the interests of this community and develop guidelines for healthcare professionals. Today, we will be looking at the missions of these groups in detail and how they've impacted patients' lives. Welcome to Cracking the Code on Peanut Allergies on Reach MD. I am your host, Dr. Jennifer Caudle, and joining me today are Dr. Anne Ellis, a Professor and Chair of the Division of Allergy Immunology and a clinician scientist at the Kingston General Hospital Research Institute in Kingston, Ontario, Canada, and George DuToit, Professor of Pediatric Allergy, Kings College London, Evelina London Children's Hospital, Guys and St. Thomas' NHS Trust. Dr. Ellis and Professor DuToit, welcome to you both.

Dr. Ellis:

Thank you. It's a pleasure to be here.

Professor DuToit:

Thank you very much for having me.

Dr. Caudle:

Absolutely. We are happy to have you both. So, let's start with you, Dr. Ellis. Can you explain the role of advocacy groups for patients with food allergies?

Dr. Ellis:

Food allergy advocacy groups have multiple roles. They often work to increase patients' knowledge about food allergies and anaphylaxis. They help them to connect with other people who are living with life-threatening food allergies. They can help to enhance coping skills for patients either at risk for food allergy reactions or, again, caregivers of those patients who have food allergies. More importantly, I think, can advocate at a national level to try to create better policies and practices nationally to protect people who are at risk for food allergy-induced reactions.

Dr. Caudle:

Excellent. Professor DuToit, what's the overall mission of these groups?

Professor DuToit:

Many groups throughout the world in their missions generally are the same and that is to support the allergy community and, of course,

there are many allergic diseases. Today we are focusing on food allergy, and the average journey for a family and, indeed, ultimately for the patients with food allergies variable over time, and the needs of these families vary enormously. We know that most allergic children will start their journey with eczema when younger, and there will be various questions and a lot of support these societies would need to give to these families and patients at that stage. Soon thereafter, many of them will develop food allergy. The food allergies will change over time. Some will be outgrown. Some will be grown into. Then, of course, in the background there is asthma and hay fever, and may patients have more than just one allergic disease, but the mission of these groups is generally to support these families over these very stressful times, particularly when these children begin nursery or creches and then they go off to school and then sleepovers and camps and tours. These all are very stressful times for families, and this is where these groups kick in.

Dr. Caudle:

Excellent. Can you give us some examples of how they educate the community?

Professor DuToit:

A very good example is recently the adrenaline autoinjectors, so these are devices that carry adrenaline that patients would self-administer when old enough for the families with a benefit to them during anaphylaxis or moderate - at least moderate reactions. There are various companies that make these products, and from time to time, there is either a shortfall in the products or a problem with product design and recall. This is extremely stressful for the community. They often will turn to these advocacy groups asking various questions about safety and access to such products.

Dr. Caudle:

Okay. You know, now I'd like to specifically talk about some popular advocacy groups like the Food Allergy and Anaphylaxis Connect Team, Asthma and Allergy Patient Advocacy, and Food Allergy Research and Education. Can you give us some insight on these groups? Dr. Ellis, why don't we address this question to you and maybe talk about the resources they provide?

Dr. Ellis:

Absolutely, so these are groups that do have a little bit of overlap in terms of their missions and their goals and their visions for the types of advocacy they're trying to provide for patients suffering from food allergy. Food Allergy and Anaphylaxis Connection Team, or FAACT for short, again really focuses on educating patients, advocating for patients, and raising awareness for all individuals with families affected by food allergies, I mean FARE or Food Allergy Research and Education, is also again a very patient-focused advocacy group but adding to again the complimentary overlap is they do provide funding for a number of research programs. The Asthma and Allergy Foundation of America adds in to not only supporting patients with food allergy but also those with anaphylaxis, again focusing on making sure that people get appropriate diagnosis, they have access to appropriate care treatment and management, and because of the asthma component, they do look into things like outdoor and indoor air quality, things like healthy homes, schools, and communities. These are all excellent advocacy groups, very similar to the one near and dear to my heart, of course, which is Food Allergy Canada, which really works hard to provide a broad support for patients with food allergy and, again, as I mentioned earlier, really lobbying at national and governmental levels to come up with better strategies and national allergy strategy to help better support patients in our communities with food allergies. In terms of -

Dr. Caudle:

Excellent.

Dr. Ellis:

In terms of specific resources, most of them have developed really nice anaphylaxis action plans, lots of resources that patients can call on for specific guidance.

Dr. Caudle:

Wonderful. For those of you who are just tuning in, you're listening to Cracking the Code on Peanut Allergies on ReachMD. I'm your host, Dr. Jennifer Caudle, and today I'm speaking with Dr. Anne Ellis and Professor George DuToit about how advocacy groups are enhancing food allergy care. So, now that we know more about the missions of these groups, I'd like to focus on the research side of things. Professor DuToit, what studies or clinical trials are currently being done by these groups to improve patient involvement in research?

Professor DuToit:

For many patients, these are exciting times. Briefly looking at prevention, I'm sure many of your listeners are aware that prevention guidelines have changed at least with regard to peanuts. Based on the LEAP study, the Learning Early About Allergies to Peanuts, and some more recent studies, such as the EAT study, the Early Acquisition of Tolerance study, both done at our center at the Evelina St. Thomas' Hospital and many other studies looking at egg throughout Europe and Australia and North America and Canada have shown that early introduction of peanut and egg is a far better strategy for the prevention of these allergies than avoidance. Focusing on treatment, there are many interesting trials. The - Probably the trials that are now gaining the most attention are those concerning oral immunotherapy, but this is a really old concept, in fact, first published over a hundred years ago where small increments of the allergen in the first test was ascribed to egg, but most of the more recent studies, such as the PALISADE study and more recently the ARTEMIS study, these are very large studies where peanuts were given in increments to patients allergic to peanuts and we see a significant upturn in the tolerance, certainly enough to be able to keep them safe from everyday accidental exposure in those patients who responded to this, but that refers to the oral route. Sublingual immunotherapy, so this is where the allergen is put under your tongue and kept there for a while as we often do with pollen immunotherapy have also long been studied. With regard to diagnostics, unfortunately our allergic patients can only, for most of them, can only undergo skin prick testing and specific IgE testing. While these are extremely helpful in certain settings and always offer a detailed clinical history, they have limitations, particularly when they are low level results

Dr. Caudle:

Excellent. That's a very comprehensive answer and really helpful to go through the different types of trials and things that are happening. So, turning to you now, Dr. Ellis, how can advocacy groups raise awareness of the services and resources they provide or is there perhaps something more we as healthcare professionals can be doing to raise awareness in addition?

Dr. Ellis:

So, all of these advocacy groups have an excellent online presence and social media performance as a way to connect with patients either through Twitter or Facebook, and I think they - they do raise a lot of awareness through those sorts of online means, but I do believe that we as healthcare practitioners should be making sure that we are communicating that these resources exist for our patients all the way from the primary care provider who is suspecting a food allergy all the way up to especially those of us who are specialists in this area and treat an awful lot of patients with food allergy. I know I certainly am always extending the information about our local advocacy groups because they do provide so much ongoing support that we, as physicians, can't always provide. Again, they're there all the time whereas we have our general visits and our follow-up visits, so they're really a great resource for our patients.

Dr. Caudle:

Wonderful. Finally, before we wrap up, I'd really like to hear any takeaways that you both might have. So, how about we start with you, Dr. Ellis?

Dr. Ellis:

I think one of the things that I've really appreciated from all of these various advocacy groups is what they've been able to accomplish to provide better protection for food-allergic patients in North America, at least on my side of the pond. Getting access to stock epinephrine in schools was a huge leap that probably wouldn't have been done if it weren't for the constant advocacy by groups like this. As I mentioned, Food Allergy Canada has created a national food allergy strategy to try to raise more awareness at the governmental level. We have really great food labeling laws in Canada now thanks to work from Food Allergy Canada, and similarly, the groups in the U.S.

are equally really involved and engaged at the national level to try to create better policies and safe practices for food - people at risk for food allergy reactions. I just can't say enough about how - what an important role they play to help those patients we look after with these food allergies.

Dr. Caudle:

Excellent, and Professor DuToit, anything to add?

Professor DuToit:

I agree wholeheartedly with Dr. Ellis that they provide amazing resources for our patients. Many of these groups also sponsor and support research, and if they're not doing that materially, they certainly are able to access patient groups, so that when we design trials and we need to take these out to patient groups, they have access to such groups and guide us and make sure that current research is relevant for patients and answers their questions, and by and large, the support that they offer to us through all form of detail, and they issue - Again, the resources of these advocacy groups provide are absolutely wonderful.

Dr. Caudle:

Wonderful. Well, considering just how far reaching the impacts of living with a food allergy can be, it's great to know that there's support and resources available to these patients. I'd really like to thank my guests, Dr. Anne Ellis and Professor George DuToit, for joining me to discuss the importance of advocacy groups. Dr. Ellis and Professor DuToit, it was wonderful having you both on the program. Thank you for being here.

Dr. Ellis:

It was a pleasure.

Professor DuToit:

Thank you very much.

Dr. Caudle:

Thank you.