

Pakistani Celiac Society

Patient education is important in the management of any disorder. This is especially true for celiac disease where the treatment is mainly dietary in nature. Well-informed patients are better able to look after their health issues.

Several countries around the world have celiac patient support organizations/associations. These include several in the USA, Canada, Australia and United Kingdom, to mention a few. Most of these are large organization with several thousand members and a well established infrastructure with plenty of resources. The concept of patient support organizations in Pakistan is not well developed.

Creation of Pakistani Celiac Society

With the above mentioned objectives of education and support, and after input from patients and health professionals, the Pakistani Celiac Society was established in 2006. The Society is a national, volunteer, non-profit, patient support organization whose aim to help patients with celiac disease.

Mission Statement

To provide support and services to individuals and families with celiac disease through programmes of awareness, advocacy and education.

Web Site

The first step in the Pakistani Celiac Society project was the establishment of a web site (www.celiac.com.pk). The web site contains detailed information on various aspects of celiac disease and the gluten-free diet both in Urdu and English. This is the first web site on celiac disease in the Urdu language. Also available are gluten-free recipes, instructions on label reading, practical tips for parents of school going children, information for travelers, printable restaurant cards and educational brochures that can be downloaded and printed.

Inauguration

The inaugural meeting of the Pakistani Celiac Society was held in March 2010 in Lahore. The meeting was attended by patients and parents of children with celiac disease, physicians, medical students, representative from the food industry, television media personnel and members of general public. The purpose of the meeting was to describe the objectives of the Society. The Society hopes to hold a meeting annually in Lahore and would also create regional chapters, with at least one in each provincial capital.

Services

A quarterly newsletter with updates on celiac disease is published, posted on the web site and circulated to all members by email. A blog helps members communicate with each other, sharing information and experiences.

Membership

Membership in the Society is currently free and available to all patients and those interested in celiac disease. A Medical Advisory Board consisting of gastroenterologists and other

health care professionals from across the country is being assembled. This is a work in progress.

Advocacy

A variety of advocacy strategies have been developed and implemented. Brochures on celiac disease are being distributed to various hospitals. Presentations on celiac disease have been held at various medical institutions. The Society will also liaise with the food industry to look at the feasibility of manufacturing affordable gluten-free products locally. Compliance with a gluten-free diet will improve if safe food is easily available and affordable.

The following example will help illustrate how advocacy can play a role for those with celiac disease. A manufacturer in Pakistan has recently marketed a brand of wheat flour (*atta*) called “Diet Atta”. The claim is that it has reduced calories and is helpful for people who are overweight or have diabetes. Along with this, the manufacturer has also labeled the wheat flour as “Gluten-Free”. This “Gluten-Free” claim is on the company’s web site and printed on the bags of the wheat flour that are being distributed all over the country. It is claimed that the wheat flour in question was tested by a laboratory in Pakistan and reported to have “Nil” gluten in it. For a poorly informed consumer on a gluten-free diet, this sounds very attractive and, in fact, life-saving. However, those who are well versed in this area know that there is no wheat flour anywhere in the world that is gluten-free. Leaving the motives of the manufacturer aside, the question is how to deal with this issue. There is little chance that the government health authorities will pay any attention to this misleading claim. It can only be through the efforts of a strong patient lobby that the manufacturer can be held accountable. This may include getting the flour analyzed for gluten content by an independent

laboratory. These types of situations will likely continue to arise in the future. Therefore, it is in the best interest of patients with celiac disease to get together to tackle these types of problems. A group can make a much more effective effort than an individual.

Creating Regional Alliances

Our neighboring countries including Iran and India have also recently formed celiac support societies. This creates great opportunities for regional alliances for cooperation and sharing of information. Most importantly, this can provide a means of manufacturing gluten-free products for the regional market, which would significantly improve the availability of such foods in these countries. It will also reduce the cost of packaged gluten-free foods as one would not have to rely on imported foreign products.

Future

Any organization is as good as its membership. Only dedicated volunteers can move the mission of the Pakistani Celiac Society forward. These individuals should be motivated and willing to donate their time and resources to further this cause. There is a need for regional representatives from all major cities who can find out about the challenges and opportunities that exist in their own communities.

The Pakistani Celiac Society is in early stage of development. One hopes that over time the organization will become a strong voice for patients with celiac disease and helps advance their cause by increasing awareness of this disorder in the country and improving availability of gluten-free products.