“Express Yourself” was a blepharospasm/Meige patient survey designed to shed light on “Who We Are.” The purpose of the project was to find out what the blepharospasm/Meige population looks like today:

- Are patients still having problems getting a diagnosis?
- Where do patients get their information?
- How is BEBRF fulfilling its role of providing patient services?

BEBRF mailed out 3,542 “Express Yourself” survey forms to blepharospasm/Meige patients in the U.S. in 2009. Glynda Lucas, BEBRF First Vice-President, and Project Director, methodically compiled all of the data received from 733 returned survey forms. Many of the patients were eager to tell their story, or voice their opinions. Therefore, they sometimes wrote on all of the available blank space on the survey form. Many of the added comments were about the difficult time they were having with their daily life. Please note that all responders did not answer all the questions. Therefore, some of the numbers may not add up.

“We are indebted to the 733 patients who took the time to fill out the surveys and shed light on “Who We Are” and create a greater awareness of the needs of BEB/Meige patients. THANK YOU.

The following information was compiled from the 733 surveys filled out by men and women who face living with a chronic disorder – BEB/Meige:
Treatments BEB/MEIGE Patients Found Helpful

- Breathing, swallowing, bruxism, and blepharitis. Many other symptoms were reported in smaller numbers.

- Diagnosis: Of the 733 participants in the survey, 503 reported to have BEB only; 212 said they have both BEB/Meige; and 16 reported Meige only. (2 did not answer the question).

- In 2001 when Dr. Padma Mahant and Dr. Mark Stacy did a similar study, the time from the development of symptoms to diagnosis had improved. Now, even more impressive, the time from symptoms to diagnosis is even shorter. Twenty-five years ago it may have taken 5 to 8 years and seeing as many as 20 doctors to get a diagnosis. The 2009 survey shows that from symptoms to diagnosis, 23% of BEB patients took less than one year to get a diagnosis; 30% took one year; and 14% took 2 years. For 47% of Meige patients, it took less than one year; for 19%, 1 year; and for 8%, it took 2 years.

- Doctors diagnosing/treating: To the question, “Who treats your blepharospasm?” the following were selected – Ophthalmologists 371; Neurologists 210; Neuro-Ophthalmologists 153; and 52 chose miscellaneous other doctors. (Multiple doctors could be chosen.)

- Diagnosing BEB patients: 45% were Ophthalmologists; 22% Neurologists; 16% Neuro-Ophthalmologists; and 17% represented miscellaneous others.

- Diagnosing Meige patients: 38% were Neurologists; 22% Ophthalmologists; 15% Neuro-Ophthalmologists; and 25% represented miscellaneous others.

- Treatments: Botulinum Toxin injections: During the past 20 years, for 90% of patients, BOTOX has continued to be the most successful treatment for BEB/Meige.

- Prescription Medications: Of the total patients responding, 35% reported drugs also helped somewhat (Klonopin/Clorazepam, Artane, Lora-....

- Other helps were warm compresses over closed eyes, tinted lenses, FL-41 tinted lenses, rest, sleep, exercise, an eye mask, singing, visors, hats, and stress reduction.

- Primary Healthcare Providers: Of patients seeking Social Security Disability, 9% received it first try; 7% after appeal; and 43% reported they were not eligible for Social Security Disability.

- Learning About BEB/Meige: Unlike the early years, today 22% of the patients learned about BEB/Meige and how to find help through the Internet and the BEBRF website; 48% were referred to the BEBRF by their doctors; 15% learned about BEBRF from other patients; and 6% learned about BEBRF from newspapers. Some of the patients listed the following as ways they learned about BEBRF: the Wall Street Journal article, magazines, BEBRF meetings, from a stranger in a restaurant who knew someone with BEB, Mattie Lou Koster, Internet, and brochures in the doctor’s office.

- Helpful BEBRF Resources: Patients chose: BEBRF Newsletter – 708; Support Group meetings - 324; BEBRF website – 206; BEBRF printed material and brochures – 340; Conferences – 216; BEBRF District Directors, State Coordinators and Area Reps. – 168; Bulletin Board – 133; and BEBRF office staff - 182. The BEBRF Newsletter was listed by 90% as being the most helpful along with “Ask the Doctor,” “Patient Stories, Volume 2,” research updates, and medical articles.

- We did find that we have a challenge before us to better inform the patients about BEBRF Research in our quest to fund research in search of a cause and cure for BEB/Meige. The BEBRF website was found to be user friendly by 265 and informative by 256, but 360 stated that they have never used the website. There was an expression of thanks for the improved website where newcomers are referred to archives more suitable to new patients and the “regulars” don’t have to read new patient info over and over. Support group meeting attendees preferred a doctor’s presentation, caring/sharing, alternative therapies, and coping skills as meeting topics. Many patients reported that there are no support groups in their areas and miss the opportunity to meet with other patients.

- We are survivors who care, share and struggle each day to find a better quality of life. 😄