

BEBRF BOARD OF DIRECTORS

Mattie Lou Koster, *Founder*
1912-2001

Mary Lou (Koster) Thompson President
Glynda Lucas 1st Vice President
Emil Weaver Treasurer
R. O. Williams Assistant Treasurer
Mary Smith Secretary
Robert B. Daroff, M.D. Advisor
Richard L. Anderson, M.D. Advisor
Ed Dondzila. Development
Nilda Rendino Advocacy
Virginia Fawcett Policy
Nell Williams William Trussell

EX OFFICIO

Mark Hallett, M.D. Chair, Medical Advisory Board
Barbara Beckett, R.N. Academy Arrangements
Bob Campbell, Ph.D. Webmaster

MEDICAL ADVISORY BOARD

Mark Hallett, M.D., Chair Bethesda, MD
L. Craig Evinger, Ph.D. Stony Brook, NY
Joseph Jankovic, M.D. Houston, TX
Laurie J. Ozelius, Ph.D. New York, NY
James R. Patrinely, M.D. Houston, TX
. and Pensacola, FL
Peter J. Savino, M.D. La Jolla, CA
Alan B. Scott, M.D. San Francisco, CA
Mark Stacy, M.D. Durham, NC
Edwardo Tolosa, M.D. Barcelona, Spain

DISTRICT DIRECTORS & E-MAIL

Anita Croce, North Central • dir-n@blepharospasm.org
Linda Peterson, Western • dir-w@blepharospasm.org
Nilda Rendino, Eastern • dir-e@blepharospasm.org
Fran Morgan, Southern • dir-s@blepharospasm.org

For further information, contact:

BENIGN ESSENTIAL BLEPHAROSPASM RESEARCH FOUNDATION

P. O. Box 12468 • Beaumont, TX 77726-2468, USA

1-409-832-0788 • Fax 1-409-832-0890

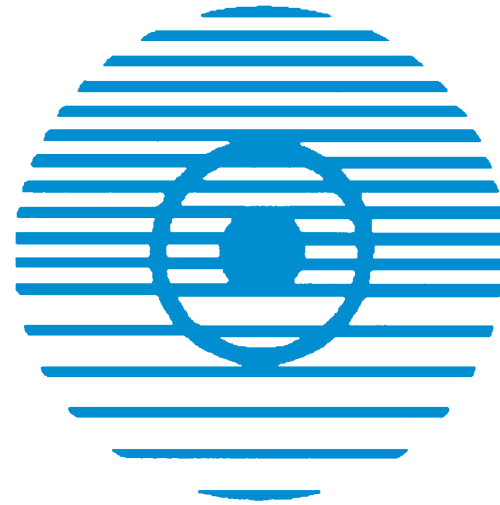
E-Mail: bebrf@blepharospasm.org

WEBSITE: <http://www.blepharospasm.org/>

BEBRF is an exempt organization under Section 501(C)(3).

All donations are tax deductible.

“EXPRESS YOURSELF”



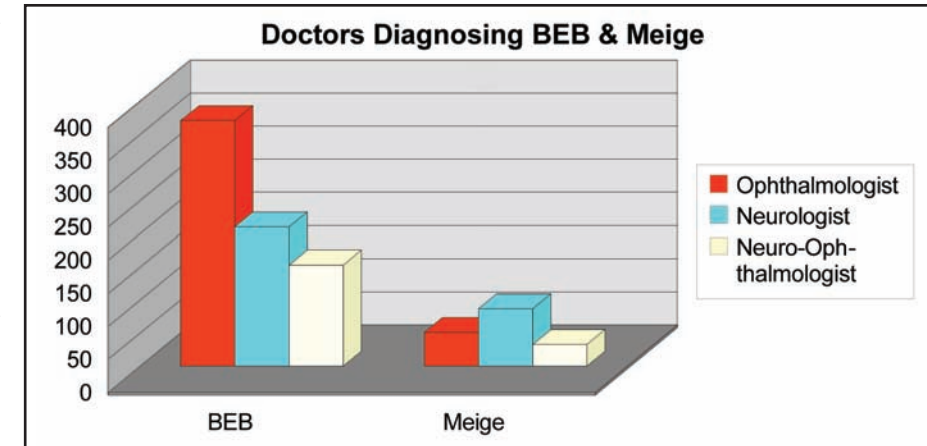
BENIGN ESSENTIAL BLEPHAROSPASM RESEARCH FOUNDATION

“EXPRESS YOURSELF” BLEPHAROSPASM/MEIGE SURVEY SUMMARY

“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?

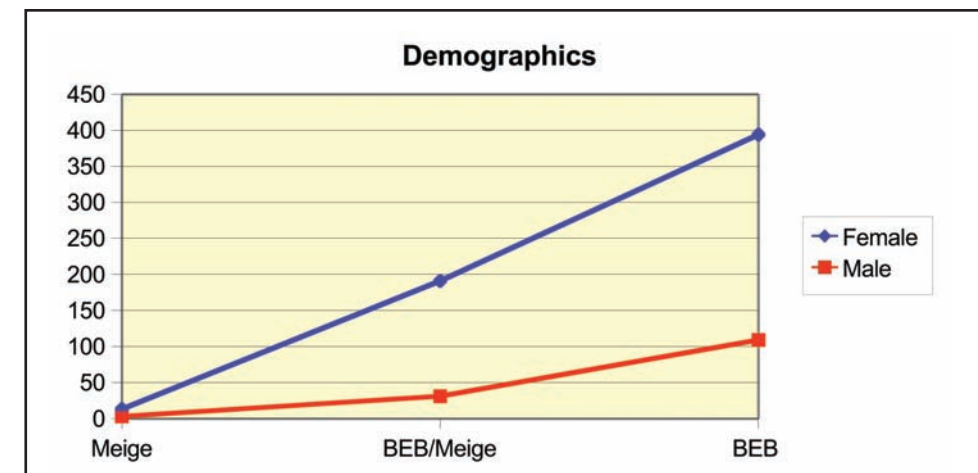
BEBRF mailed out 3,542 “Express Yourself” survey forms to blepharospasm/Meige patients in the U.S. in 2009. Glynda Lucas, BEBRF First Vice-President, and Project Director, methodically compiled all of the data received from 733 returned survey forms. Many of the patients were eager to tell their story, 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



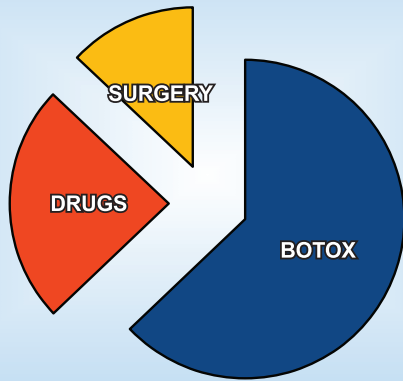
difficult time they were having with their daily life. Please note that all responders did not answer all the questions. Therefore, some of the numbers may not add up.

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: **OPEN >**



Treatments BEB/MEIGE Patients Found Helpful



Who Are We? – Responders data:

Total	Male	Female
733	143	588
BEB	109	394
Meige	3	13
BEB/Meige	31	181
Avg. Age	69	69
Oldest	95	93
Youngest	21	39

Male & Female: Family member with related movement disorder: 64. No known family member with related movement disorder: 595. Unsure, but suspected cases that were undiagnosed: 72.

Symptoms: The survey revealed that the top three BEB /Meige symptoms were: light sensitivity – 648; spasms that close the eyelids – 582; difficulty keeping eyes open - 567. Others had difficulty with

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® continues to be the most successful treatment for BEB/Meige.

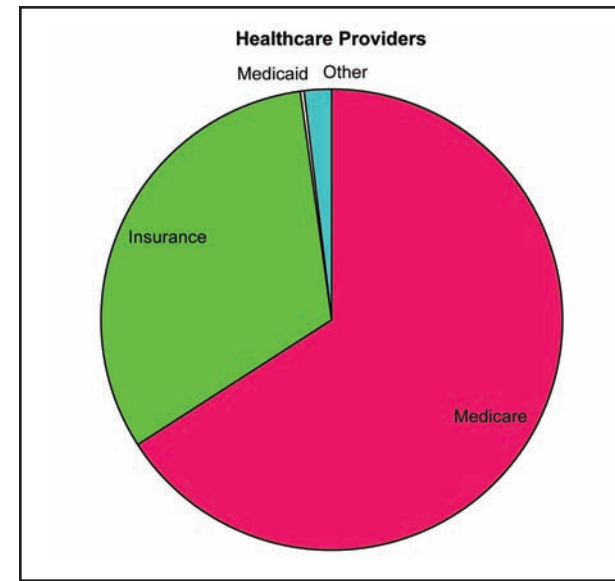
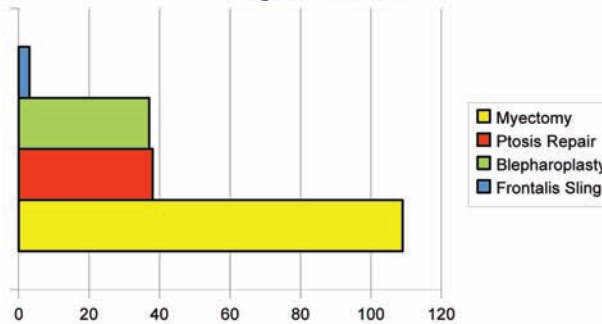
Prescription Medications: Of the total patients responding, 35% reported drugs also helped somewhat (Klonopin/Clorazepam, Artane, Lorazepam, Ativan, Baclofen and Restasis).

Surgery: 26% of the total patients responding reported that surgery had helped them – Myectomy-109; Ptosis Repair-38; Blepharoplasty-37; and Frontalis sling-3.

Over-the-counter: Products listed as being helpful were Benadryl and flaxseed oil.

Eye drops were widely used – **For daytime use:** 76 used Refresh; 59 Systane; 48 Genteal; 39 Thera Tears; 23 Optive; and 20 Refresh Plus. **For nighttime use:** 12 used Genteal Severe Dry Eye; 12 Lacrilube; and 12 Refresh PM.

Surgical Treatment



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: Medicare-66%; Insurance (employer or private) - 32%; No Insurance-1%; Medicaid-4%; and Other-1%.

Employment Status: Of BEB/Meige patients, 64% are now retired; 20% are still working; and 14% are not employed because of BEB/Meige problems. Some of the comments were: “ability to listen and pay attention is more difficult due to blinking/fighting facial movement; I reduced the lighting in my office; I can no longer do the things on the farm that I used to do; too much stress; reduced productivity; I shy away from co-workers.”

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 BEB/Meige website; 48% were referred to the BEB/Meige by their doctors; 15% learned about BEB/Meige from other patients; and

6% learned about BEB/Meige from newspapers. Some of the patients listed the following as ways they learned about BEB/Meige: the Wall Street Journal article, magazines, BEB/Meige meetings, from a stranger in a restaurant who knew someone with BEB, Mattie Lou Koster, Internet, and brochures in the doctor's office.

Helpful BEB/Meige Resources: Patients chose: BEB/Meige Newsletter – 708; Support Group meetings - 324; BEB/Meige website – 206; BEB/Meige printed material and brochures – 340; Conferences – 216; BEB/Meige District Directors, State Coordinators and Area Reps. – 168; Bulletin Board – 133; and BEB/Meige office staff - 182. The BEB/Meige 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 BEB/Meige Research in our quest to fund research in search of a cause and cure for BEB/Meige. The BEB/Meige 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.

SO WHO ARE WE? WE ARE SURVIVORS, who care, share and struggle each day to find a better quality of life. 🌟

Helpful BEB/Meige Resources

