

# A Patient-Oriented Eye-Condition Rating Kit

Prepared for  
Benign Essential Blepharospasm  
Canadian Research Foundation, Inc.

by

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## INTRODUCTION

Jankovic et al. (1982) developed a rating scale for blepharospasm that was oriented from the viewpoint of the examining physician. There were, in fact, two scales: one for **Severity**, the other for **Frequency**. Scores for each scale ranged from zero (no symptoms) to four (for the worst case). The sum of the two scores represents the overall Jankovic scale. Table 1, from Iwashige et al. (1995), shows the details. Dr Noelene Pang, who presented a proposed experiment on repeated injections of botulinum toxin at the October 23, 2005 BEBCRF Meeting, plans to use a Jankovic scale of six for selection of patients for the experiment. [See *BEB Newsletter* 11:2:3-8 (February 1, 2006).] I am grateful to Dr Pang for providing a copy of the Iwashige et al paper.

## PATIENT-ORIENTED RATING SCHEME

Unlike physicians, who are often most interested in the **high-score** cases, patients tend to look at their condition the opposite way, with high scores for the best days, somewhat like an Olympic diving competition, as Dr Stephen Kraft has been known to comment.

This project arose from personal experience. For five years, I kept a daily record of my eye condition from shortly after I was diagnosed with BEB in 1997, through several treatments of Botox™, and myectomy and frontalis-sling surgeries. My doctors (Stephen Kraft and David Jordan) found that this semi-objective feedback following treatment was quite helpful to them. I was therefore asked by BEBCRF to prepare this rating kit for use by other BEB patients and to write this brief explanation.

My rating scheme is shown near the top of Table 2. The individual may wish to change the definitions; however, my choice was to define a score of 10 as a spasm-free day, nine as a very good day (occasional spasms), eight as a good day, (some spasms, but generally not too bothersome), seven as a fair day (frequent, short spasms), six as a poor day (frequent, longer spasms), five as an awful day (eyes closed much of the time). Scores below five were reserved for even worse than awful, but fortunately I never needed them.

One could use half-scores, for example 7.5, if one could not decide between seven and eight. I used 9.5 on occasion and 9.9 once or twice, but never achieved a 10.

For patients with eyelid apraxia, the word **closure** can be substituted for **spasm**.

### **HOW TO USE THE RATING KIT**

To use this rating kit, enter your daily score in Table 2. Attached are an example and a blank version. The latter should be used as a master copy to make photocopies.

At the end of each week, the scores are totalled and the resulting sum is divided by seven to give the weekly average, which is transferred to Table 3. Again, an example and a blank version (master copy) of Table 3 are attached.

The Averages for Weeks 0 to 8 of Table 2 (intended to give a Baseline before treatment) are entered in the third column of in Table 3. In this example, Week 9 in Table 2 is the week of treatment (Botox, new medication or surgery, for example) when the average for that week (marked by \*) is transferred to Week 0 of the fourth column in Table 3. In this example, Weeks 10 to 21 are also copied to the fourth column of Table 3. Continue in this manner, each time starting a new column in Table 3 with the average for the week of treatment as the new Week 0. In the example given, Weeks 4-14 of the fifth column in Table 3 would have come from a second page of the example Table 2.

## **OPTIONAL PLOTTING OF WEEKLY AVERAGES**

As an option, the results of Table 3 may be plotted column-by-column in Figure 1 (attached). The averages of the example Table-3 columns were plotted using a computer; however, the same result can be obtained by manually plotting on graph paper (0.25 inch or 0.5 cm squares would work well). I used a spacing of about 1 inch (2.5 cm) between Average scores on the vertical axis of Figure 1. For manual plotting, 0.25 cm per 0.1 of eye-condition score would be advisable.

For the horizontal axis, my spacing was about 0.4 cm per week, though for graph paper, one square (e.g., 0.25 inch or 0.5 cm), would be more appropriate. Use different colours and/or symbols or lines joining the points to distinguish one line from another. After about three or four curves, start a new graph.

## **OTHER FACTORS**

Finally, there may be side effects such as sensitivity to light or wind, dry eyes, reaction to medication or botulinum toxin, any of which can cause a poor eye day. It may be difficult to separate these side effects from BEB or apraxia, and it may not be necessary to do so. On the other hand, the patient may wish to distinguish the cause of problems on individual days by recording them in a diary or by keeping separate records called, for example, **Treatment and Side Effects**.

My hope is that this rating kit will be mutually beneficial to BEB patients and their ophthalmic surgeons.

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**Table 1. The Jankovic rating scale<sup>1,2</sup>**

		-
Severity	0	None
	1	Increase in blinking present only with external stimuli (e.g., bright light, wind, reading, driving, etc.)
	2	Mild but spontaneous eyelid fluttering (without actual spasm), definitely noticeable, possibly embarrassing, but not functionally disabling
	3	Moderate, very noticeable spasm of eyelids only, mildly incapacitating
	4	Severe, incapacitating spasm of eyelids and possibly other facial muscles
		-
Frequency	0	None
	1	Slightly increased frequency of blinking
	2	Eyelid fluttering lasting less than one second in duration
	3	Eyelid spasm lasting more than one second, but eyes open more than 50% of waking time
	4	Functionally blind due to persistent eye closure (blepharospasm) more than 50% of waking time

<sup>1</sup> Iwashige H, Nemeto Y, Takahashi H & Maruo T: (1995) Botulinum Toxin Type A Purified Neurotoxin Complex for the Treatment of Blepharospasm: A Dose-Response Study Measuring Eyelid Force. *Jpn J Ophthalmol* **39**: 424-431

<sup>2</sup> Jankovic J, Havins WE & Wilkins RB: (1982) Blinking and blepharospasm: mechanism, diagnosis, and management: *JAMA* **248**: 3160-3164

## Table 2. Example Rating Sheet

Daily Scores of Eye Condition																										
10=perfect, 9=Very Good, 8=Good, 7=Fair, 6=Poor, 5=Awful																										
Week	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
Day																										
Sun	6	8	7	6	7	7	7	7	7	7	8	7	8	8	7	8	6	8	7	7	7	7	6	7	7	7
Mon	5	8	6	8	7	7	6	8	8	7	8	7	8	9	7	9	7	8	7	6	6	6	6	8	7	8
Tue	8	8	7	9	7	7	6	9	7	7	7	8	9	9	7	7	7	8	7	7	7	7	7	7	8	8
Wed	7	8	8	9	7	6	6	9	7	7	8	8	9	9	8	7	7	9	7	7	6	7	7	9	8	7
Thu	5	8	8	8	8	8	6	9	7	8	9	8	8	9	8	7	6	9	7	7	7	7	6	9	9	8
Fri	6	9	8	9	8	8	7	7	7	7	8	8	9	8	8	7	7	8	7	7	7	8	8	9	9	8
Sat	7	9	7	8	8	7	7	8	5	7	8	8	8	8	7	7	8	8	7	6	7	7	7	7	8	9
<b>Total</b>	44	58	51	57	52	50	45	57	48	50	56	54	59	60	52	52	48	58	49	47	47	49	47	56	56	55
<b>Average</b>	6.3	8.3	7.3	8.1	7.4	7.1	6.4	8.1	6.9	7.1	8.0	7.7	8.4	8.6	7.4	7.4	6.9	8.3	7.0	6.7	6.7	7.0	6.7	8.0	8.0	7.9
	*									*													*			

**Note: \* indicates week of treatment. The marked average is transferred to Week 0 in Table 3.**

**Table 3. Example Weekly Averages**

Weekly average eye condition				
	Event	Start	Botox	Botox
	Units		60	90
	Year	2005	2005	2006
	Month	9	11	2
	Day	7	16	15
Week				
0		6.3	7.1	6.7
1		8.3	8.0	8.0
2		7.3	7.7	8.0
3		8.1	8.4	7.9
4		7.4	8.6	8.4
5		7.1	7.4	7.9
6		6.4	7.4	7.9
7		8.1	6.9	7.4
8		6.9	8.3	8.0
9			7.0	7.6
10			6.7	7.6
11			6.7	7.4
12			7.0	8.3
13				7.3
14				7.3
<p><b>Note: Week 0 begins the Sunday before treatment.</b>  <b>Week of treatment is indicated by * at bottom of Table 2.</b></p>				

## Table 2. Daily Rating Sheet

<b>Daily Scores of Eye Condition</b>																										
<b>10=perfect, 9=Very Good, 8=Good, 7=Fair, 6=Poor, 5=Awful</b>																										
<b>Week</b>	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
<b>Day</b>																										
Sun																										
Mon																										
Tue																										
Wed																										
Thu																										
Fri																										
Sat																										
<b>Total</b>																										
<b>Average</b>																										
<b>Note: * indicates week of treatment. The marked average is transferred to Week 0 in Table 3. ©2006 BEBCRF</b>																										

**Table 3. Weekly Averages**

**Weekly average eye condition**

	<b>Event</b>												
	<b>Units</b>												
	<b>Year</b>												
	<b>Month</b>												
	<b>Day</b>												
<b>Week</b>													
0													
1													
2													
3													
4													
5													
6													
7													
8													
9													
10													
11													
12													
13													
14													

**Note: Week 0 begins the Sunday before treatment.  
Week of treatment is indicated by \* at bottom of Table 2.**



FIGURE 1.  
EXAMPLE PLOT OF WEEKLY AVERAGES

