

Summary of survey on Idebenone use
 March 2005

Number of responses		13
Age		
10 and under		2
11 to 14		7
20 to 30		3
30 and over		1
Male		7
Female		6
Time on Idebenone		
0 to 6 months		3
7 to 12 months		4
1+ to 2 years		2
2+ to 3 years		2
3+ years		2
Dosage (rounded to nearest 5 mg/kg/d)		
5		5
10		6
15+		2
(highest dose used is 18)		
Other meds commonly taken		
Vitamin E		10
400 IU	1	
800 IU	6	
1200 IU	1	
unspecified	2	
CoQ10		5
300 mg	2	
600 mg	2	
unspecified	1	
Multivitamin		4
NAC		2
L-Carnitine		2
Alpha lipoic acid		2
Vitamin C		2
Selenium		3
Atenelol (or other beta blocker)		2

Side effects noted

Nobody reports any side effects

hypertrophic cardiomyopathy (HCM)?

Yes	9
No	4

Change in HCM since starting Idebenone?

Decrease	2 (1)
Stable	3 (2)
Increase	1 (3)
Too soon to tell	3
N/A (no HCM)	4

Notes:

- (1) One patient had dramatic decrease (18mm to 9mm) over 3 years.
One patient saw reversal starting between 6 and 12 months.
- (2) Taking Idebenone for relatively brief time compared to time since diagnosis.
Might these patients be naturally stable?
9 months taking Idebenone / Dx 13 years ago
9 mo / 8 yrs
8 mo / 5 yrs
- (3) 12mm to 15mm over past 7 months, only taking Idebenone for 3 months.

Other changes noted

Less tired / more energy	5
Balance / clumsiness improves	2

Idebenone source

Kirkman Labs	6
Smart Nutrition (or Smart Drugs)	5
Government (non U.S.)	1
local pharmacy	1

Cost paid varies. Mostly the same as on the various websites for the above sources.

Interest in group purchases (if possible)

Yes (includes already doing so)	11
No	2