



Interstitial Cystitis Data Base

Patient ID: _____

Date: ____ / ____ / ____
month day year

Opinion Survey

Your opinions about participating in the Interstitial Cystitis Data Base Study are important to us. Your answers to this survey will help us learn what you thought about the Interstitial Cystitis Data Base Study. **Most importantly**, your answers will also help us to better prepare for future studies. Please answer all of the questions, place your Opinion Survey Form in the enclosed envelope, seal it, and return it to your *Research Coordinator*. The sealed envelope will be sent **UNOPENED** to the Interstitial Cystitis Data Base Data Coordinating Center in Hershey, Pennsylvania.

No one at your clinical center will see your answers to this survey. Your answers will be kept strictly confidential. In order to maintain confidentiality, please do **NOT** sign or write your name on this form.

1. Why did you decide to **enroll** in the Interstitial Cystitis Data Base study? Please indicate **Yes** or **No** for each of the statements listed below.

	Yes (1)	No (0)
A. Close, frequent monitoring of my bladder condition		
B. Meet medical personnel familiar with Interstitial Cystitis		
C. Meet others with my disease		
D. Learn more about Interstitial Cystitis and bladder disease		
E. Learn about new treatments for my bladder condition		
F. Help others with Interstitial Cystitis or urinary bladder disorders		
G. Improve my overall health		
H. Take part in research		
I. My doctor recommended it		
J. My family wanted me to be in the study		
K. Curiosity- I wanted to give it a try		
L. Other Please specify: _____		

2. Which of the following played a part in your decision to **continue** your participation in the Interstitial Cystitis Data Base Study? Please indicate **Yes** or **No** for each of the statements listed below.

	Yes (1)	No (0)
A. Close, frequent monitoring of my bladder condition		
B. Help others with Interstitial Cystitis or urinary bladder disorders		
C. Take part in research		
D. Further the general knowledge and understanding of Interstitial Cystitis		
E. Help find a cure for Interstitial Cystitis		
F. My relationship with the Interstitial Cystitis Data Base Study physician(s)		
G. My relationship with the Interstitial Cystitis Data Base Research Coordinator(s)		
H. I received up-to-date information on Interstitial Cystitis		
I. My overall health improved		
J. Other Please specify: _____		

3. Who do you feel was helped by your participation in the Interstitial Cystitis Data Base Study? Please indicate **Yes** or **No** for each of the statements listed below.

	Yes (1)	No (0)
A. Myself		
B. Scientists		
C. The Interstitial Cystitis Data Base Staff		
D. Other people with bladder disease		

4. If you were asked in the future to take part in a study *like* the Interstitial Cystitis Data Base Study, would you volunteer?
- ₁ Yes
- ₀ No
5. Would you recommend taking part in a study *like* the Interstitial Cystitis Data Base Study to a friend or a family member who was thinking about volunteering?
- ₁ Yes
- ₀ No
6. Would you be interested in being contacted for future studies on Interstitial Cystitis?
- ₁ Yes
- ₀ No
7. Would you be interested in a clinical trial comparing therapies for treatment of Interstitial Cystitis?
- ₁ Yes
- ₀ No
8. Compared to the **beginning of your study participation**, how would you rate your **urinary symptoms** now?
- ₁ Much better
- ₂ Somewhat better
- ₃ About the same
- ₄ Somewhat worse
- ₅ Much worse
9. Compared to the **beginning of your study participation**, how would you rate your **general health** now?
- ₁ Much better
- ₂ Somewhat better
- ₃ No effect
- ₄ Somewhat worse
- ₅ Much worse

10. Please rate how often the items below have been a problem for you during your participation in the Interstitial Cystitis Data Base Study? Please indicate *one* response for each statement listed below.

	Always (4)	Often (3)	Sometimes (2)	Rarely (1)	Never (0)
A. Travel to and from the clinic					
B. Parking					
C. Location of the clinic					
D. Long waits for clinic visits					
E. Hurried clinic visits					
F. Clinic visits take too much time					
G. Too many clinic visits					
H. Inconvenient scheduling of visits					
I. Changes in the staff at the Interstitial Cystitis Data Base clinics					
J. Difficulty taking time off from work					
K. Family problems related to my visits, <i>for example; care for children, sick parents, elderly parents</i>					
L. Family disapproved of my participation					
M. Cost of participating in the Interstitial Cystitis Data Base Study					