

**NIDDK IBD Genetics Consortium  
Crohn's Disease Phenotype Form**

**Registration Information**

Individual ID: \_\_\_\_\_  
 Mother's ID: \_\_\_\_\_  
 Father's ID: \_\_\_\_\_  
 Family No.: \_\_\_\_\_

Gender:  Male  Female  
 Date of birth:   /   /      
 Consortium ID:       -

Affix sample label here

**Demographic and Diagnostic Information**

Hispanic:  Yes  No  Unknown  
 Jewish:  Yes  No  Unknown  
 Race:  White  American Indian/Alaskan  
            Black/African American  Native Hawaiian/<sup>Native</sup> Pacific Islander  
            Asian  Unknown  
            Other (specify: \_\_\_\_\_)  
 Is grandparent Jewish?      If Jewish, Ashkenazi?  
           Yes    No    Unknown      Yes    No    Unknown  
 Paternal grandfather:                  
 Paternal grandmother:                  
 Maternal grandfather:                  
 Maternal grandmother:             

Year of diagnosis:          Latest clinical exam/encounter:   /   /

	CD	UC/IC	IBD affected (type unclear)	Unaffected	Unknown	
Father:	<input type="radio"/>					
Mother:	<input type="radio"/>					
No. siblings:	<input type="text"/> <input type="text"/>	(sum of row should equal total no. of siblings)				
No. children:	<input type="text"/> <input type="text"/>	(sum of row should equal total no. of children)				

Family history of IBD in 2nd degree relatives:  Yes  No  Unknown  
 If family history of IBD, indicate family type:  
 CD  Mixed  Unknown

**Smoking History Prior to Diagnosis**

Smoking at diagnosis:  Yes  Ex-smoker  No  Unknown (1 pack = 20 cigarettes)  
 If yes or ex-smoker: Year started:     Year stopped:     No. of cigarettes per day:    Unknown

**Macroscopic Disease Location (check all that apply)**

Upper GI:  Yes  No  Unknown      Colorectal:  Yes  No  Unknown  
 Jejunal:  Yes  No  Unknown      Perianal/Perineal:  Yes  No  Unknown  
 Ileal:  Yes  No  Unknown      CD disease behavior:  B1  B2  B3  Unknown

**FORM IS CONTINUED ON BACK**



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**Surgery**

Surgery for complication or treatment of CD:  Yes  No  Unknown

Year of first operation:

If yes: Bowel resection/strictureplasty:  Yes  No  Unknown

Diversion:  Yes  No  Unknown

Abdominal fistula/abscess:  Yes  No  Unknown

Perineal fistula/abscess:  Yes  No  Unknown

No. of operations for abdominal disease:  
(i.e., resection, strictureplasty, abscess drainage)

No. of operations for perineal disease:  
(including diversions)

Appendectomy:  Yes  No  Unknown

If yes, indicate year:      Unknown

**Extra-Intestinal Manifestations**

Joints: Large joint related to disease activity:  Yes  No  Unknown

Small joint unrelated to disease activity:  Yes  No  Unknown

Ankylosing spondylitis:  Yes  No  Unknown

Sacro-iliitis:  Yes  No  Unknown

Non-specific joint inflammation:  Yes  No  Unknown

Eyes: Uveitis:  Yes  No  Unknown

Episcleritis:  Yes  No  Unknown

Undiagnosed ocular inflammation:  Yes  No  Unknown

Liver: Primary sclerosing cholangitis:  Yes  No  Unknown

Skin: Erythema nodosum:  Yes  No  Unknown

Pyoderma:  Yes  No  Unknown

Completed by: \_\_\_\_\_

Date:   /   /



**NIDDK IBD Genetics Consortium  
UC/IC Phenotype Form**

**Registration Information**

Individual ID: \_\_\_\_\_  
 Mother's ID: \_\_\_\_\_  
 Father's ID: \_\_\_\_\_  
 Family No.: \_\_\_\_\_

Disease type:  UC  IC  
 Gender:  Male  Female  
 Date of birth:   /   /      
 Consortium ID:       -

Affix sample label here

**Demographic and Diagnostic Information**

Hispanic:  Yes  No  Unknown  
 Jewish:  Yes  No  Unknown  
 Race:  White  American Indian/Alaskan  
            Black/African American  Native Hawaiian/<sup>Native</sup> Pacific Islander  
            Asian  Unknown  
            Other (specify: \_\_\_\_\_ )

Is grandparent Jewish?      If Jewish, Ashkenazi?  
           Yes    No    Unknown      Yes    No    Unknown

Paternal grandfather:             
 Paternal grandmother:             
 Maternal grandfather:             
 Maternal grandmother:        

Year of diagnosis:          Latest clinical exam/encounter:   /   /

	CD	UC/IC	IBD affected (type unclear)	Unaffected	Unknown	
Father:	<input type="radio"/>					
Mother:	<input type="radio"/>					
No. siblings:	<input type="text"/> <input type="text"/>	(sum of row should equal total no. of siblings)				
No. children:	<input type="text"/> <input type="text"/>	(sum of row should equal total no. of children)				

Family history of IBD in 2nd degree relatives:  Yes  No  Unknown  
 If family history of IBD, indicate family type:  
 UC  Mixed  Unknown

**Smoking History Prior to Diagnosis**

Smoking at diagnosis:  Yes  Ex-smoker  No  Unknown (1 pack = 20 cigarettes)  
 If yes or ex-smoker: Year started:     Year stopped:     No. of cigarettes per day:    Unknown

**Macroscopic Disease Location (check all that apply)**

Proctitis:  Yes  No  Unknown  
 Left-sided (to splenic flexure):  Yes  No  Unknown  
 Extensive (beyond splenic flexure):  Yes  No  Unknown  
 Periappendiceal inflammation:  Yes  No  Unknown

**FORM IS CONTINUED ON BACK**



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UC/IC Phenotype Form

**Surgery**

Surgery for complication or treatment of UC:  Yes  No  Unknown

If yes: Surgery for dysplasia/cancer:  Yes  No  Unknown

Surgery for chronic continuous disease:  Yes  No  Unknown

Surgery for acute fulminant disease:  Yes  No  Unknown

Year of surgery (colectomy):

Diagnosis of dysplasia/cancer (colorectal):  Yes  No  Unknown

Appendectomy:  Yes  No  Unknown

If yes, indicate year:      Unknown

**Extra-Intestinal Manifestations**

Joints: Large joint related to disease activity:  Yes  No  Unknown

Small joint unrelated to disease activity:  Yes  No  Unknown

Ankylosing spondylitis:  Yes  No  Unknown

Sacro-iliitis:  Yes  No  Unknown

Non-specific joint inflammation:  Yes  No  Unknown

Eyes: Uveitis:  Yes  No  Unknown

Episcleritis:  Yes  No  Unknown

Undiagnosed ocular inflammation:  Yes  No  Unknown

Liver: Primary sclerosing cholangitis:  Yes  No  Unknown

Skin: Erythema nodosum:  Yes  No  Unknown

Pyoderma:  Yes  No  Unknown

Completed by: \_\_\_\_\_

Date:   /   /



**NIDDK IBD Genetics Consortium  
Unaffected Phenotype Form**

**Registration Information**

Individual ID: \_\_\_\_\_

Gender:  Male  Female

Family No.: \_\_\_\_\_

Date of birth:   /   /

*Affix sample label here*

Consortium ID:     -

Relationship to proband:  Parent  Spouse/Domestic Partner  Friend  Population Control

- Control checklist:  Within 10 years of age of index subject (*controls for pediatric cases (<18) cannot be more than 24 years old*)  
*(controls only)*  Same race/ethnicity as index subject  
 No family history of IBD  
 Never been diagnosed with IBD  
 Never experienced chronic diarrhea, unexplained rectal bleeding, or unexplained weight loss

**Demographic Information**

Hispanic:  Yes  No  Unknown

Race:  White  American Indian/Alaskan  
 Black/African American  Native Hawaiian/  
 Asian  Unknown  Pacific Islander  
 Other (specify: \_\_\_\_\_)

Jewish:  Yes  No  Unknown

	Is grandparent Jewish?			If Jewish, Ashkenazi?		
	Yes	No	Unknown	Yes	No	Unknown

Paternal grandfather:  Yes  No  Unknown  Yes  No  Unknown

Paternal grandmother:  Yes  No  Unknown  Yes  No  Unknown

Maternal grandfather:  Yes  No  Unknown  Yes  No  Unknown

Maternal grandmother:  Yes  No  Unknown  Yes  No  Unknown

If spouse/domestic partner, duration of cohabitation:   years  Unknown

**Smoking History**

Smoking status:  Current smoker  Ex-smoker  Non-smoker  Unknown *(1 pack = 20 cigarettes)*

If current or ex-smoker: Year started:    Year stopped:    No. of cigarettes per day:    Unknown

**Surgery**

Appendectomy:  Yes  No  Unknown

If yes, indicate year:      Unknown

Completed by: \_\_\_\_\_ Date:   /   /

