

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

Version 1.2
26-Jan-04
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Registration Information

Individual ID: _____
Mother's ID: _____
Father's ID: _____
Family No.: _____

Gender: ☐ Male ☐ Female

Date of birth:

M	M
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 /

D	D
---	---

 /

Y	Y	Y	Y
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Affix sample label here

Consortium ID:

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Demographic and Diagnostic Information

Hispanic: ☐ Yes ☐ No ☐ Unknown

Race: ☐ White

☐ American Indian/Alaskan

Jewish: ☐ Yes ☐ No ☐ Unknown

☐ Black/African American

☐ Native Hawaiian/ Native Pacific Islander

Is grandparent Jewish?

If Jewish, Ashkenazi?

☐ Asian

☐ Unknown

☐ Other (specify: _____)

Yes No Unknown

Yes No Unknown

Paternal grandfather: ☐ ☐ ☐ ☐ ☐ ☐

Paternal grandmother: ☐ ☐ ☐ ☐ ☐ ☐

Maternal grandfather: ☐ ☐ ☐ ☐ ☐ ☐

Maternal grandmother: ☐ ☐ ☐ ☐ ☐ ☐

Year of diagnosis:

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Latest clinical exam/encounter:

M	M
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D	D
---	---

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Y	Y	Y	Y
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	CD	UC/IC	IBD affected (type unclear)	Unaffected	Unknown
Father:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mother:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

No. siblings:

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(sum of row should equal total no. of siblings)

No. children:

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(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:

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 Year stopped:

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 No. of cigarettes per day:

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☐ Unknown

Macroscopic Disease Location (check all that apply)

Upper GI: ☐ Yes ☐ No ☐ Unknown

Colorectal: ☐ Yes ☐ No ☐ Unknown

Jejunum: ☐ Yes ☐ No ☐ Unknown

Perianal/Perineal: ☐ Yes ☐ No ☐ Unknown

Ileal: ☐ Yes ☐ No ☐ Unknown

CD disease behavior: ☐ B1 ☐ B2 ☐ B3 ☐ Unknown

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Surgery

Surgery for complication or treatment of CD: ☐ Yes ☐ No ☐ Unknown

Year of first operation:

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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)

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

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Appendectomy: ☐ Yes ☐ No ☐ Unknown

If yes, indicate year:

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☐ 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:

M	M	/	D	D	/	Y	Y	Y	Y
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**NIDDK IBD Genetics Consortium
UC/IC Phenotype Form**

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26-Jan-04

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Registration Information

Individual ID: _____
Mother's ID: _____
Father's ID: _____
Family No.: _____

Disease type: ☐ UC ☐ IC

Gender: ☐ Male ☐ Female

Date of birth:

M	M
---	---

 /

D	D
---	---

 /

Y	Y	Y	Y
---	---	---	---

Affix sample label here

Consortium ID:

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Demographic and Diagnostic Information

Hispanic: ☐ Yes ☐ No ☐ Unknown

Race: ☐ White

☐ American Indian/Alaskan

Jewish: ☐ Yes ☐ No ☐ Unknown

☐ Black/African American

☐ Native Hawaiian/ Native Pacific Islander

Is grandparent Jewish?

Yes No Unknown

If Jewish, Ashkenazi?

Yes No Unknown

☐ Asian

☐ Unknown

☐ Other (specify: _____)

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

Year of diagnosis:

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Latest clinical exam/encounter:

M	M
---	---

 /

D	D
---	---

 /

Y	Y	Y	Y
---	---	---	---

	CD	UC/IC	IBD affected (type unclear)	Unaffected	Unknown											
Father:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>											
Mother:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>											
No. siblings:	<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			(sum of row should equal total no. of siblings)
No. children:	<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			<table border="1" style="display: inline-table; vertical-align: middle;"><tr><td> </td><td> </td></tr></table>			(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:

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 Year stopped:

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 No. of cigarettes per day:

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☐ Unknown

Macroscopic Disease Location (check all that apply)

Proctitis: ☐ Yes ☐ No ☐ Unknown

Extensive (beyond
splenic flexure):

☐ Yes ☐ No ☐ Unknown

Left-sided (to
splenic flexure): ☐ Yes ☐ No ☐ Unknown

Periappendiceal inflammation: ☐ Yes ☐ No ☐ Unknown

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UC/IC Phenotype Form

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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):

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

Appendectomy: ☐ Yes ☐ No ☐ Unknown

If yes, indicate year:

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☐ 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:

M	M	/	D	D	/	Y	Y	Y	Y
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NIDDK IBD Genetics Consortium
Unaffected Phenotype Form

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26-Jan-04

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Registration Information

Individual ID: _____

Gender: ☐ Male ☐ Female

Family No.: _____

Date of birth: MM / DD / YYYY

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

Jewish: ☐ Yes ☐ No ☐ Unknown

Race: ☐ White

☐ American Indian/Alaskan

☐ Black/African American ☐ Native Hawaiian/
Native

☐ Asian

☐ Unknown Pacific Islander

☐ Other (specify: _____)

Is grandparent Jewish?

Yes No Unknown

If Jewish, Ashkenazi?

Yes No Unknown

Paternal grandfather: ☐ Yes ☐ No ☐ Unknown

Paternal grandmother: ☐ Yes ☐ No ☐ Unknown

Maternal grandfather: ☐ Yes ☐ No ☐ Unknown

Maternal grandmother: ☐ 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: MM / DD / YYYY

