



IBR Specialty Clinical Laboratories

1050 Forest Hill Road, Staten Island, New York 10314-6399
(718) 494-5345 fax (718) 494-0694 CLIA #33D0860102

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MOLECULAR TESTING FOR BATTEN DISEASE

PATIENT NAME Last _____ First _____ M.I. _____			Date of Birth MM ____ DD ____ YY ____			Sex M ____ F ____	
Address Street _____ City _____ State _____ Zip _____		Telephone _____			Fax _____		
ETHNIC BACKGROUND: Maternal: grandfather [____], grandmother [____], Paternal: grandfather [____], grandmother [____]							

CLINICAL INFORMATION	
Client is: [____] Affected, [____] Father, [____] Mother, [____] Sibling, [____] Other (specify): _____	
History of the affected: First Symptom (Please describe and attach a summary): _____ Age at Onset _____	
Previous Biopsy [____] Yes [____] No	If Yes, indicate [____] Blood Buffy Coat [____] Skin Punch
Pathological Finding (attach a copy of report) : [____] fingerprint, [____] curvilinear, [____] granular, [____] mixed, [____] other _____	
Clinical Diagnosis: [____] INCL [____] LINCL [____] JNCL [____] ANCL [____] Other _____	

REFERRAL INFORMATION			
Physician Name: _____	Telephone # _____	Fax # _____	E-mail: _____
Address: _____	City _____	State _____	Zip _____
Genetic Counselor _____	Telephone _____	Fax _____	E-mail _____
Has affected or other family member been tested previously? [____] No [____] Yes, If Yes, when ____ (mm)/____ (dd)/____ (yy), [____] IBR _____ (Name of the affected person), [____] Elsewhere _____ (Name of the Institution and attach a copy of report).			

BILLING INFORMATION	
Contact _____	Name of Insured: _____
Hospital/Laboratory _____	Relationship to the patient (circle): Self Spouse Child Other _____
Street Address _____	Insurance Company _____ ID # _____
City, State, Zip _____	Attach a copy of both sides of patient's insurance card
Telephone # _____ Fax # _____	

SPECIMEN INFORMATION		Date Collected : ____ (mm)/____ (dd)/____ (yy).
Please label each specimen clearly with Client's Name, DOB, Relationship (such as: affected, sib, father, mother, etc.) and date collected. Specimens should be shipped overnight at room temperature in an insulated container and received Monday to Thursday by overnight EXPRESS.		
Postnatal: [____] Blood: 5 ml in green tube for banking,	[____] Blood: 5 ml in lavender tube for DNA Test,	[____] Isolated DNA (>10mg)
Prenatal (Must Have Authorization From Our Laboratory Prior To Scheduling Procedure): [____] CVS: 10-20 mg in sterile tube [____] Amniotic Fluid: 25 ml in sterile tube [____] Cultured CVS [____] Cultured AF		
Is a pregnancy involved? [____] No [____] Yes If yes, date of LMP ____ (mm)/____ (dd) / ____ (yr). Gestational age by ultrasound: ____ weeks ____ days		

FOR LABORATORY USE ONLY			
Date Received ____ / ____ / ____	Receiver: _____	SCL Accession # _____	
Lab Log # _____	Family # _____	DNA# _____	Culture # _____
Comments: 			



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INFORMED CONSENT: The purpose of this test is to determine whether or not the 1.02-kb deletion on the CLN3 gene for Batten disease (NCL3) has occurred in the subject. Detection of the 1.02-kb deletion indicates the subject is affected by, or is a carrier for, Batten disease. The test is ~99% accurate. However, because about 5-25% of individuals with Batten disease do not carry this 1.02-kb deletion, a negative test result does not definitively rule out being affected by Batten disease.

[] I give consent for diagnostic testing only. I understand that my specimen/sample will be destroyed within 60 days after the test is completed.

Consent for diagnostic testing only (Signature and date)

[] I give consent, if no 1.02-kb deletion is detected in the present test, for the remaining specimen/sample to be kept for an indefinite period of time by the laboratory and to be used for research. This research will investigate different CLN3 mutation(s) or other NCL loci and will be performed with Institutional Review Board approval. I understand that my specimen/sample will be coded to protect my confidentiality and that I may withdraw my permission without penalty, at which time my specimen will be destroyed.

Consent for diagnostic testing and for use of remaining sample for research (Signature and date)

Note: The information on this referral form is confidential and is under the protection of the HIPPA Privacy Rule of 1996. If it has arrived at the wrong address, please destroy this form and notify us as soon as possible. Thank you.