



Complement Deficiency Registry Data Collection Form

Patient Initials: ____/____/____

Patient Identification:

Patient Name (first, middle, last) _____

Patient's USIDNET Registry Number assigned after online enrollment _____

Date of Birth ____/____/____(mm/dd/yyyy) or Year of Birth _____

Gender: male female

Home Address:

Address: _____

State: _____

Zip Code: _____

Phone: _____

Email: _____

State or Province of birth: _____

Country of birth: _____

Date of this Record Completion (mm/dd/yyyy): ____/____/____

Date of Visit (mm/dd/yyyy): ____/____/____

Is this the initial registration of this patient or follow-up?

Submitting Physician Information:

Name: _____

Address: _____

State: _____

Zip Code: _____

Phone: _____

Email: _____

Fax: _____

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Diagnostic Criteria:

Tests Performed (complete for all that apply)

Test	Value	Unit of Measure	Please list normal range for your lab
CH50 level		Units	
AH50 level		Units	
C1 esterase inhibitor functional test		%	
C1 esterase inhibitor antigen level		g/L	
MBL level		ng/ml	

Deficient individual component serum level (specify component(s): _____)

Antigen level: _____ (please list normal range _____)

Individual component functional assay (specify component _____) result _____

Immunoglobulin G Subclasses

IgG1 _____ mg/dl
IgG2 _____ mg/dl
IgG3 _____ mg/dl
IgG4 _____ mg/dl

Genetic Information

Sporadic (no family history) or _____ pattern of inheritance
Family history unknown []
Specify affected family member (s) _____

For MBL:

Was a polymorphism identified? Yes No Unknown
Polymorphism? (please identify) _____

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Pedigree Analysis

Family history unknown

Consanguinity-Parents related? (explain) _____

Please list additional relationships. If more space is needed, please use the Memo section at the end of this form.

Relation	Living	Deceased	Normal	Affected	Not Tested	Carrier	Unknown	Undiagnosed with Suggestive Symptoms
Mother								
Father								

Information on other affected kindred members listed above (e.g., sibling, cousin, &/or maternal uncle)

Relationship	Initials	Gender	Year of Birth	Listed in Registry? Yes/No/Unknown

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Gene Mutation

(Number nucleotides using Human Mutation 11:1-3, 1998)

Was mutation analysis performed? Yes No Unknown
 Specify gene(s) tested _____
 Mutation analysis performed by _____
 Nucleotides affected (eg A229C) _____
 Predicted amino acid change (eg T33P) _____
 Insertion / Deletion / Frameshift / Splice Site (please explain) _____
 Mutation tested but not found gene _____
 Publications (please give citation - if published) _____
 Mutant protein expressed? Yes No Not tested Test used? _____

Other Treatments/Procedures Used:

Plasma Infusions? Yes No Unknown
 For what purpose? _____

Additional Clinical Features of Special Interest Please Check

Angioedema	Not Seen	Observed	Prominent Feature	Unknown
Oral swelling				
Laryngeal swelling				
Facial swelling				
Extremity swelling				
Bowel swelling				
Tracheostomy				
Appendectomy				

Organ Damage	Not Seen	Observed	Prominent Feature	Unknown
Cutaneous scarring				
CNS damage				
Deafness				
Renal failure				

Organ Damage (continued)	Yes	No	Unknown
Has the patient ever been intubated?			
Renal transplant			
Joint replacement			

Number of episodes of meningitis _____
 Was meningitis the problem that led to diagnostic testing? Yes No Unknown
 Associated organisms and serotypes _____

