



Common Variable Immune Deficiency and Other Hypogammaglobulinemias
Registry Data Collection Form

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: _____

CVID Registry Data Collection Form

Patient Initials: ___/___/___

Diagnostic Criteria For CVID Only - Skip this section for all Hypogammaglobulinemias except CVID.

Probable []

Male or female patient who has a marked decrease (at least 2 SD below the mean for age) in two out of three of the major isotypes including IgG (IgG and IgA or IgM) and fulfills **all of the following criteria**:

- Onset of immunodeficiency at greater than 2 years of age []
- Absent isohemagglutinins and/or poor response to vaccines []
- Defined causes of hypogammaglobulinemia have been excluded []

Possible []

Male or female patient who has a marked decrease (at least 2 SD below the mean for age) in IgG and fulfills **all of the following criteria**:

- Onset of immunodeficiency at greater than 2 years of age []
- Absent isohemagglutinins and/or poor response to vaccines []
- Defined causes of hypogammaglobulinemia have been excluded []

Tests Performed

Indicate those tests / data used to establish / confirm the diagnosis by checking the indicated box []

Additional Immunoglobulins		
IgG1		mg/dl
IgG2		mg/dl
IgG3		mg/dl
IgG4		mg/dl

Memory B cell phenotype		% of B cells
CD27+ B cells	Total memory B cells	
CD27+ IgM+ B cells	IgM memory B cells	
CD27+ IgD- B cells	Switched memory B cells	

Genetic Information

Pattern of inheritance:

Sporadic (no prior family history) [] X-linked [] autosomal recessive [] Unknown []

Pedigree Analysis

Family history unknown []

Consanguinity-Parents related? (explain) _____

CVID Registry Data Collection Form

Patient Initials: ___/___/___

Pedigree Analysis

Indicate number living & dead in each category and then note the presence of listed disorders in members of the patient's family.

Relation		Living	Deceased	Normal	CVID/ Hypogammaglobulinemia	Selective IgA deficiency	IG subclass deficiency	Transient Hypogammaglobulinemia	SLE (Lupus erythematosis)	Dermatomyositis	Rheumatoid arthritis	Inflammatory bowel disease	Sarcoidosis/Granulomatous disease	ITP	Autoimmune hemolytic anemia	Thyroiditis	Leukemia or lymphoma	Other Malignancy	Not tested	Medical History Unknown
Mother	(fill in # for each category)																			
Father																				
Brothers																				
Sisters																				
Sons																				
Daughters																				
Uncles	(fill in # for each category and indicate (M)aternal or (P)aternal)																			
Aunts																				
Cousins																				
Grandfather																				
Grandmother																				
Other (explain)																				

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

CVID Registry Data Collection Form

Patient Initials: ___/___/___

Gene Mutation

Mutations found? ICOS [], TACI [], CD19 [], _____

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

Nucleotides affected (e.g., 361C>T) _____

Predicted Amino Acid Change (e.g., W140R) _____

Insertion / Deletion / Frameshift / Splice Site (please explain) _____

Mutation tested for but not found [] gene _____

Publications or mutation database (please give citation - if published) _____

Protein/Enzyme expressed? Yes___, No___, Not tested_____ Which tested? _____

Cytokines

	Yes	No	Unknown	Age		OR Date (mm/dd/yyyy)	Response
				Mos.	Yrs.		
Gamma-interferon							
G-CSF							
GM-CSF							
IL-2							
Other (list):							

Other treatments used

	Yes	No	Unknown	Age begun		Date begun (mm/dd/yyyy)	Duration	Still needed?	
				Mos.	Yrs.			Yes	No
Chronic oxygen									
Parenteral nutrition									
Other									

Other? Please explain _____

Additional comments:
