USIDNET Paper Forms

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USIDNET Registry Visit

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CRF: PARTICIPANT INFORMATION

Participant Name	
Participant is de-identified	◯ Yes ◯ No
First Name	______________________________
Middle Name	______________________________
Last Name	______________________________
Maiden / Other Name	______________________________
Patient Initials	______________________________

Participant Information	
Date of Birth	______ / _______ / _______
State of Birth	________________________
Sex	◯ Male ◯ Female

Race and Ethnicity	
Participant race **(check all that apply)**	□ Caucasian / White □ American Indian / Alaska Native □ Asian □ Native Hawaiian or Pacific Islander □ Black or African American □ More than One Race □ Other (specify) _______________ □ Unknown or Not Reported
Participant is Hispanic or Latino	◯ Yes ◯ No

Contact Information	
Address	______________________________
City	______________________________
State	______________________________
Zip	______________________________
Phone	______________________________
Email	______________________________

CRF: CONSENT INFORMATION

Participant Consent	
Note: Unconsented data must be de-identified	
Consent Type	◯ Institution-Specific IRB ◯ Schulman IRB ◯ IRB Waiver
Reason for waiver	◯ Patient is deceased ◯ Other ______________________
Per consent, patient allows USIDNET to contact him/her.	◯ Yes ◯ No
Per consent, patient allows USIDNET to contact his/her physician.	◯ Yes ◯ No
Consent allows sharing of data with CIBMTR and related research data platforms.	◯ Yes ◯ No
CIBMTR Recipient ID Number	___________________________________
PIDTC Recipient ID Number	___________________________________
Additional data platforms per consent (if applicable)	___________________________________ ___________________________________ ___________________________________ ___________________________________ ___________________________________ ___________________________________ ___________________________________

CRF: FAMILY HISTORY

Family History of PI	
Are there other patients with a primary immunodeficiency in the family?	◯ Yes ◯ No ◯ Unknown
How many relatives also have a PI?	______________________________
Did a positive family history prompt testing of this patient?	◯ Yes ◯ No ◯ Unknown
Are the parents of the patient related to each other?	◯ Yes ◯ No ◯ Unknown

Information on Affected Family Members		
Relation	**Diagnosis**	**Listed in Registry?**
______________________________	______________________________	◯ Yes ◯ No ◯ Unknown
______________________________	______________________________	◯ Yes ◯ No ◯ Unknown
______________________________	______________________________	◯ Yes ◯ No ◯ Unknown
______________________________	______________________________	◯ Yes ◯ No ◯ Unknown
______________________________	______________________________	◯ Yes ◯ No ◯ Unknown
______________________________	______________________________	◯ Yes ◯ No ◯ Unknown
______________________________	______________________________	◯ Yes ◯ No ◯ Unknown

Family History of Other Diseases		
	Has family history of disease	**Disease present in…**
Autoimmune Diseases	◯ Yes ◯ No ◯ Unknown	□ Mother □ Father □ Sister □ Brother □ Daughter □ Son □ Other Female Relative □ Other Male Relative □ Relative Not Specified
Inflammatory Diseases	◯ Yes ◯ No ◯ Unknown	□ Mother □ Father □ Sister □ Brother □ Daughter □ Son □ Other Female Relative □ Other Male Relative □ Relative Not Specified
Malignancies	◯ Yes ◯ No ◯ Unknown	□ Mother □ Father □ Sister □ Brother □ Daughter □ Son □ Other Female Relative □ Other Male Relative □ Relative Not Specified

Family History of Other Diseases			
Relation	**Genetic Testing Done**	**Test Results**	**Gene Tested**
____________________________	◯ Yes ◯ No ◯ Unknown	◯ No Pathologic Variants ◯ X-Recessive Carrier ◯ Autosomal Recessive Carrier ◯ Same variant as proband without current health issues ◯ Unknown	________________
____________________________	◯ Yes ◯ No ◯ Unknown	◯ No Pathologic Variants ◯ X-Recessive Carrier ◯ Autosomal Recessive Carrier ◯ Same variant as proband without current health issues ◯ Unknown	________________
____________________________	◯ Yes ◯ No ◯ Unknown	◯ No Pathologic Variants ◯ X-Recessive Carrier ◯ Autosomal Recessive Carrier ◯ Same variant as proband without current health issues ◯ Unknown	________________
____________________________	◯ Yes ◯ No ◯ Unknown	◯ No Pathologic Variants ◯ X-Recessive Carrier ◯ Autosomal Recessive Carrier ◯ Same variant as proband without current health issues ◯ Unknown	________________
____________________________	◯ Yes ◯ No ◯ Unknown	◯ No Pathologic Variants ◯ X-Recessive Carrier ◯ Autosomal Recessive Carrier ◯ Same variant as proband without current health issues ◯ Unknown	________________
____________________________	◯ Yes ◯ No ◯ Unknown	◯ No Pathologic Variants ◯ X-Recessive Carrier ◯ Autosomal Recessive Carrier ◯ Same variant as proband without current health issues ◯ Unknown	________________
____________________________	◯ Yes ◯ No ◯ Unknown	◯ No Pathologic Variants ◯ X-Recessive Carrier ◯ Autosomal Recessive Carrier ◯ Same variant as proband without current health issues ◯ Unknown	________________

USIDNET Registry Visit

CRF: VISIT INFORMATION

Dates	
Most recent date covered in this visit	______ / _______ / _______

Current Diagnosis	
Current Diagnosis **Select best fitting diagnosis from the list**	◯ Agammaglobulinemia ◯ Ataxia Telangiectasia ◯ Autoimmune Lymphoproliferative Syndrome (ALPS) ◯ Autoinflammatory disease ◯ CHARGE Syndrome ◯ Chronic Granulomatous Disease ◯ Combined Immune Deficiency ◯ Common Variable Immune Deficiency (CVID) ◯ Complement Deficiency ◯ DiGeorge Syndrome ◯ Dyskeratosis Congenita ◯ Ectodermal Dysplasia with Immunodeficiency (NEMO and others) ◯ Hemophagocytic Lymphohistiocytosis Syndrome (HLH, including XLP & pigment disorders) ◯ Hyper IgE Syndrome ◯ Hyper IgM Syndrome ◯ Hypogammaglobulinemia ◯ IgA Deficiency ◯ IgG Subclass Deficiency ◯ Immune Dysregulation ◯ Immunodeficiency with myelodysplasia (GATA2 and others) ◯ Interferonopathy (Aicardi-Goutieres and others) ◯ Leukocyte adhesion deficiency ◯ Mucocutaneous candidiasis ◯ Neutropenia ◯ NK Cell Defect ◯ Omenn syndrome ◯ Other Neutrophil Problems ◯ Other T-Cell Problems ◯ Predisposition to severe viral infections ◯ Severe Combined Immune Deficiency (SCID) ◯ Specific antibody deficiency with normal Ig concentrations and normal numbers of B cells ◯ Susceptibility to mycobacteria (MSMD) ◯ Thymoma with Immune deficiency (Good syndrome) ◯ TLR Pathway Abnormality ◯ Transient hypogammaglobulinemia of infancy with normal numbers of B cells ◯ Wiskott-Aldrich Syndrome ◯ Immune deficiency with syndromic features (Not otherwise listed) ◯ Other Immune Deficiency – Known Cause ◯ Immunodeficiency Unknown Cause

CRF: VITALS / MEASURES

Vitals		
Date of Measurement:	**Date** **Age (months)** **Age (years)**	______ / _______ / _______ ________________________________ ________________________________
Vitals:	**Select Units**	◯ Standard (USA) ◯ Metric
	Centimeters **Feet** **Inches**	________________________ cm ________________________ ft ________________________ in
	Kilograms **Pounds** **Ounces**	________________________ kg ________________________ lb ________________________ oz
Head Circumference:	**Select Units**	◯ Standard (USA) ◯ Metric
	Centimeters **Inches**	________________________________ ________________________________

CRF: CLINICAL HISTORY

Diagnostic Timeline		
Onset of Symptoms:	**Select Format**	◯ Enter Date of Onset ◯ Enter Age of Onset ◯ Date and Age Unknown
	Date	______ / _______ / _______
	Age	__________________________ months __________________________ years
Diagnosis Established:	**Select Format**	◯ Enter Date of Onset ◯ Enter Age of Onset ◯ Date and Age Unknown
	Date	______ / _______ / _______
	Age (months)	__________________________ months
	Age (years)	__________________________ years

Infections			
Infection Name	**Present *before* *or at* diagnosis?**	**This infection *is a...***	**Organism(s)**
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________
______________________	◯ Yes ◯ No ◯ Unknown	◯ New instance ◯ Continuing Issue ◯ Unknown	______________________________ ______________________________ ______________________________

Systemic or Organ Specific Conditions		
Condition Name	**Present *before or at* diagnosis?**	**Condition *persists* at this visit**
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
______________________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown

Allergic Reactions	
Agent	**Reaction**
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown
◯ Food ◯ Drug (specify) ____________________ ◯ Environmental ◯ Other (specify) ____________________ ◯ Unknown	________________________________ ☐ Reaction Unknown

Malignancies			
Name of Cancer	**Present *before or at* diagnosis?**	**Presents *currently* (at visit)?**	**How Treated?**
____________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	☐ Surgery ☐ Radiation ☐ Chemotherapy ☐ Biologic (specify) ________________ ☐ Other ☐ Unknown
____________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	☐ Surgery ☐ Radiation ☐ Chemotherapy ☐ Biologic (specify) ________________ ☐ Other ☐ Unknown
____________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	☐ Surgery ☐ Radiation ☐ Chemotherapy ☐ Biologic (specify) ________________ ☐ Other ☐ Unknown
____________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	☐ Surgery ☐ Radiation ☐ Chemotherapy ☐ Biologic (specify) ________________ ☐ Other ☐ Unknown
____________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	☐ Surgery ☐ Radiation ☐ Chemotherapy ☐ Biologic (specify) ________________ ☐ Other ☐ Unknown
____________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	☐ Surgery ☐ Radiation ☐ Chemotherapy ☐ Biologic (specify) ________________ ☐ Other ☐ Unknown
____________________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	☐ Surgery ☐ Radiation ☐ Chemotherapy ☐ Biologic (specify) ________________ ☐ Other ☐ Unknown

Vaccine Reactions		
Vaccine	**Adverse Reaction**	**Reaction**
BCG	◯ Yes ◯ No ◯ Unknown	___________________________________
Flumist	◯ Yes ◯ No ◯ Unknown	___________________________________
Measles (MMR)	◯ Yes ◯ No ◯ Unknown	___________________________________
Rotavirus	◯ Yes ◯ No ◯ Unknown	___________________________________
Vaccinia	◯ Yes ◯ No ◯ Unknown	___________________________________
Varicella	◯ Yes ◯ No ◯ Unknown	___________________________________
Yellow Fever	◯ Yes ◯ No ◯ Unknown	___________________________________
__________________________	◯ Yes ◯ No ◯ Unknown	___________________________________
__________________________	◯ Yes ◯ No ◯ Unknown	___________________________________
__________________________	◯ Yes ◯ No ◯ Unknown	___________________________________
__________________________	◯ Yes ◯ No ◯ Unknown	___________________________________
__________________________	◯ Yes ◯ No ◯ Unknown	___________________________________

Immunoglobulin Infusions		
Has patient ever received Ig Replacement Therapy?		◯ Yes ◯ No ◯ Unknown
Is patient currently on Ig replacement therapy?		◯ Yes ◯ No ◯ Unknown
Initiation	**Start Date** **Start Age**	_____ / _____ / _____ ___________________ months ___________________ years
Termination	**End Date** **End Age**	_____ / _____ / _____ ___________________ months ___________________ years
Dose		_________________________ mg/kg _________________________ Total grams
Route		◯ IV ◯ SC ◯ IM ◯ Unknown ◯ Other ____________________
Frequency		____________________________ days
Was a port placed specifically for IVIG?		◯ Yes ◯ No ◯ Unknown

Reactions to Ig Treatment	
Mild = noted by patient but required no intervention Moderate = required medical intervention Severe = required hospitalization	
Reaction	**Severity**
____	◯ Mild ◯ Moderate ◯ Severe
____	◯ Mild ◯ Moderate ◯ Severe
____	◯ Mild ◯ Moderate ◯ Severe
____	◯ Mild ◯ Moderate ◯ Severe

Transfusion Treatments	
Patient has received a blood transfusion	◯ Yes ◯ No ◯ Unknown
Transfusion Type	☐ Leukocyte ☐ Platelet ☐ Red Cell ☐ Fresh Frozen Plasma ☐ Whole Blood ☐ Unknown Type

CRF: MEDICATIONS AND SUPPLEMENTS

Historical Anti-Infective Treatment	
Patient has used anti-infective medication in the past year	◯ Yes ◯ No ◯ Unknown
How many courses of antibiotic treatment has the patient required for *active infection* in the past year? *Note: please enter "0" if no antibiotics have been used	________________________

Prophylactic Anti-Infectives			
Please include all antibiotics, anti-virals, and anti-fungals (topical and systemic)			
Drug Name	**Course**	**Adverse Reaction**	**Reaction**
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________
______________	☐ Continuous ☐ Intermittent ☐ Rotating	◯ Yes ◯ No ◯ Unknown	______________

Other Anti-Infective Medications					
Please include all antibiotics, anti-virals, and anti-fungals (topical and systemic)					
Drug Name	**Indication**	**Infection**	**Outcome**	**Adverse Reaction**	**Reaction**
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________
______________	◯ Acute Infection ◯ Chronic Infection ◯ Unknown	____________	◯ Resolved ◯ Unresolved ◯ Unknown	◯ Yes ◯ No ◯ Unknown	______________

Historical Immunomodulator Treatment	
Patient has used immunomodulatory medication in the past year	◯ Yes ◯ No ◯ Unknown

Non-Transplant Immunomodulator Medications					
Please include all immunomodulator medications prescribed during the time period of this visit					
Drug Name	**Indication**	**Specify**	**Improvement**	**Adverse Reaction**	**Reaction**
____________	◯ Treat Disease ◯ Prophylaxis ◯ Unknown	____________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	____________
____________	◯ Treat Disease ◯ Prophylaxis ◯ Unknown	____________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	____________
____________	◯ Treat Disease ◯ Prophylaxis ◯ Unknown	____________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	____________
____________	◯ Treat Disease ◯ Prophylaxis ◯ Unknown	____________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	____________
____________	◯ Treat Disease ◯ Prophylaxis ◯ Unknown	____________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	____________
____________	◯ Treat Disease ◯ Prophylaxis ◯ Unknown	____________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	____________
____________	◯ Treat Disease ◯ Prophylaxis ◯ Unknown	____________	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown	____________

For-Transplant Immunomodulator Medication			
Please include all immunomodulator medications prescribed during the time period of this visit			
Drug Name	**Indication**	**Adverse Reaction**	**Reaction**
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________
________________	◯ Stem Cell: PRE-transplant ◯ Stem Cell: POST-transplant ◯ Organ: PRE-transplant ◯ Organ: POST-transplant ◯ Unknown	◯ Yes ◯ No ◯ Unknown	________________

Additional Medications		
Please enter all current probiotics, supplements, and medications that do not apply to either of the previous sections.		
Drug Name	**Adverse Reaction?**	**Reaction**
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________
______________________________	◯ Yes ◯ No ◯ Unknown	_____________________________________

CRF: SURGERIES AND PROCEDURES

Surgical and Diagnostic Procedures

Please enter all historical and relevant procedures relevant to this participant's primary immunodeficiency.

Procedure Name	Date
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______
______________________________	_____/ ______/ ______

Nutritional Support		
Type	**Date Began**	**Still Needed?**
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown
◯ Enteral nutrition ◯ Parenteral nutrition ◯ Other _______________	______ / _______ / _______	◯ Yes ◯ No ◯ Unknown

Respiratory Support		
Type	**Date Began**	**Still Needed?**
◯ ECMO ◯ Intubation > 2 days ◯ CPAP ◯ BiPAP ◯ Oxygen (unknown type) ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ ECMO ◯ Intubation > 2 days ◯ CPAP ◯ BiPAP ◯ Oxygen (unknown type) ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ ECMO ◯ Intubation > 2 days ◯ CPAP ◯ BiPAP ◯ Oxygen (unknown type) ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ ECMO ◯ Intubation > 2 days ◯ CPAP ◯ BiPAP ◯ Oxygen (unknown type) ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ ECMO ◯ Intubation > 2 days ◯ CPAP ◯ BiPAP ◯ Oxygen (unknown type) ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ ECMO ◯ Intubation > 2 days ◯ CPAP ◯ BiPAP ◯ Oxygen (unknown type) ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ ECMO ◯ Intubation > 2 days ◯ CPAP ◯ BiPAP ◯ Oxygen (unknown type) ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown

Therapy and Educational Support		
Type	**Date Began**	**Still Needed?**
◯ Individualized Educational Plan ◯ Mental health services ◯ Occupational therapy ◯ Physical Therapy ◯ Speech Therapy ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ Individualized Educational Plan ◯ Mental health services ◯ Occupational therapy ◯ Physical Therapy ◯ Speech Therapy ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ Individualized Educational Plan ◯ Mental health services ◯ Occupational therapy ◯ Physical Therapy ◯ Speech Therapy ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ Individualized Educational Plan ◯ Mental health services ◯ Occupational therapy ◯ Physical Therapy ◯ Speech Therapy ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ Individualized Educational Plan ◯ Mental health services ◯ Occupational therapy ◯ Physical Therapy ◯ Speech Therapy ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown
◯ Individualized Educational Plan ◯ Mental health services ◯ Occupational therapy ◯ Physical Therapy ◯ Speech Therapy ◯ Other ___________________	______/ _______/ _______	◯ Yes ◯ No ◯ Unknown

Other Treatments	
Does this patient regularly use any of the following to manage their primary immunodeficiency? (Select all that apply)	☐ Chiropractor ☐ Acupuncture ☐ Herbal remedies ☐ Homeopathic practitioners ☐ Other ______________________

CRF: TRANSPLANTATION AND GENE THERAPY

Transplantation	
Patient has undergone transplant	◯ Yes ◯ No ◯ Unknown
Type of transplant	☐ Hematopoietic Stem Cells ☐ Solid Organ ☐ Unknown

Stem Cell Transplant		
	#1	**#2**
		◯ Booster ◯ Full ◯ Unspecified
Date of Transplant **Date** **Age**	______ / _______ / _______ _____________ months _____________ years	______ / _______ / _______ _____________ months _____________ years
Most significant reason for SCT	◯ Primary immune deficiency ◯ Malignancy ◯ Autoimmunity	◯ Primary immune deficiency ◯ Malignancy ◯ Autoimmunity
Donor	◯ Sibling – full match ◯ Sibling – partial match ◯ Haploidentical – parental ◯ Other related – full match ◯ Other related – partial match ◯ Unrelated – full match ◯ Unrelated – partial match ◯ Unknown	◯ Sibling – full match ◯ Sibling – partial match ◯ Haploidentical – parental ◯ Other related – full match ◯ Other related – partial match ◯ Unrelated – full match ◯ Unrelated – partial match ◯ Unknown
Source of Graft	◯ Mobilized peripheral blood ◯ Cord blood ◯ Bone marrow ◯ Unknown	◯ Mobilized peripheral blood ◯ Cord blood ◯ Bone marrow ◯ Unknown
Purification of Stem Cells	◯ T Cell Depleted ◯ Unfractionated ◯ CD34 Enriched ◯ Unknown	◯ T Cell Depleted ◯ Unfractionated ◯ CD34 Enriched ◯ Unknown
Conditioning Used	◯ Myeloablative ◯ Minimal intensity conditioning ◯ Reduced intensity conditioning ◯ Immunosuppression only ◯ No conditioning ◯ Unknown	◯ Myeloablative ◯ Minimal intensity conditioning ◯ Reduced intensity conditioning ◯ Immunosuppression only ◯ No conditioning ◯ Unknown

	#1	#2
Was radiation used during conditioning?	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
Did engraftment occur? (neutrophils have appeared)	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
Engraftment: days post-transplant	____________________	____________________

Chimerism State	Definition
Complete chimerism	100% donor cells detected, suggesting complete hematopoietic replacement
Mixed chimerism	5%-90% donor cells detected. Host cells detected in particular cells (e.g. lymphocytes)
Split chimerism	Some cell lineages are 100% donor & some are 100% host
Microchimerism	Less than 1% host cells detected

Chimerism State	◯ Complete Chimerism ◯ Mixed Chimerism ◯ Split Chimerism ◯ Microchimerism ◯ Unknown	◯ Complete Chimerism ◯ Mixed Chimerism ◯ Split Chimerism ◯ Microchimerism ◯ Unknown
Date of Chimerism	______ / _______ / _______	______ / _______ / _______

GVHD					
Type	**GVHD?**	**Organs Involved**	**Grade**	**Treatment**	**Still Active?**
Acute GVHD	◯ Yes ◯ No ◯ Unknown	□ Skin □ Liver □ GI Tract	◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ Unknown	________________ ________________ ________________	◯ Yes ◯ No ◯ Unknown
Chronic GVHD	◯ Yes ◯ No ◯ Unknown	□ Skin □ Liver □ GI Tract	◯ Extensive ◯ Limited ◯ Not Known	________________ ________________ ________________	◯ Yes ◯ No ◯ Unknown

Solid Organ Transplant		
	#1	**#2**
Date of Transplant **Date** **Age**	______ / _______ / _______ _____________ months _____________ years	______ / _______ / _______ _____________ months _____________ years
Reason for Transplant	◯ Thymic Aplasia ◯ Organ Damage ◯ Congenital Abnormality ◯ Other ___________________ ◯ Unknown	◯ Thymic Aplasia ◯ Organ Damage ◯ Congenital Abnormality ◯ Other ___________________ ◯ Unknown
Donor	◯ Cadaver ◯ Related Living ◯ Unrelated Living ◯ Unknown	◯ Cadaver ◯ Related Living ◯ Unrelated Living ◯ Unknown
Immunosuppression Medication?	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
Drug Name	___________________________ ___________________________ ___________________________	___________________________ ___________________________ ___________________________
Which Solid Organ?	◯ Kidney ◯ Liver ◯ Lung ◯ Heart ◯ Cornea ◯ Thymus ◯ Intestines ◯ Other ___________________	◯ Kidney ◯ Liver ◯ Lung ◯ Heart ◯ Cornea ◯ Thymus ◯ Intestines ◯ Other ___________________
Outcome	◯ Stable with good function ◯ Stable with acceptable function ◯ Not stable / re-transplant probable ◯ Rejected and re-transplanted ◯ Rejected ◯ Unknown	◯ Stable with good function ◯ Stable with acceptable function ◯ Not stable / re-transplant probable ◯ Rejected and re-transplanted ◯ Rejected ◯ Unknown

Transplant Not Performed	
Transplant considered and not performed?	◯ Yes ◯ No
Solid Organ (reason)	☐ Lack of donor ☐ Age or condition of the patient ☐ Unfavorable probability of success ☐ Religious objections ☐ Insurance denial ☐ Hyper-immune status ☐ Other ____________________
Hematopoietic Stem Cell Transplant	☐ Lack of donor ☐ Age or condition of the patient ☐ Unfavorable probability of success ☐ Religious objections ☐ Insurance denial ☐ Other _______________________

Gene Therapy		
Patient has undergone gene therapy	◯ Yes ◯ No ◯ Unknown	
	#1	**#2**
Date of GT **Date** **Age**	______ / _______ / _______ _____________ months _____________ years	______ / _______ / _______ _____________ months _____________ years
Specify Gene	______________________________	______________________________
Specify Vector Type	◯ Gamma-retrovirus ◯ Lentivirus ◯ Self-inactivating retrovirus ◯ Self-inactivating lentivirus ◯ Other ____________________ ◯ Unknown	◯ Gamma-retrovirus ◯ Lentivirus ◯ Self-inactivating retrovirus ◯ Self-inactivating lentivirus ◯ Other ____________________ ◯ Unknown
Which Cells Transduced?	◯ Bone marrow CD34+ cells ◯ Peripheral blood mobilized CD34+ ◯ Peripheral blood T cells ◯ Other ____________________ ◯ Unknown	◯ Bone marrow CD34+ cells ◯ Peripheral blood mobilized CD34+ ◯ Peripheral blood T cells ◯ Other ____________________ ◯ Unknown
Conditioning Used	◯ Myeloablative ◯ Minimal intensity conditioning ◯ Reduced intensity conditioning ◯ Immunosuppression only ◯ No conditioning ◯ Unknown	◯ Myeloablative ◯ Minimal intensity conditioning ◯ Reduced intensity conditioning ◯ Immunosuppression only ◯ No conditioning ◯ Unknown

	#1	#2
Results	◯ Full correction ◯ Partial correction ◯ Disease not corrected ◯ Other ____________________ ◯ Unknown	◯ Full correction ◯ Partial correction ◯ Disease not corrected ◯ Other ____________________ ◯ Unknown
Complications?	◯ Yes ◯ No ◯ Unknown	◯ Yes ◯ No ◯ Unknown
Describe	☐ Myelodysplasia ☐ Autoimmunity ☐ Leukemia ☐ Other ____________________ ☐ Unknown	☐ Myelodysplasia ☐ Autoimmunity ☐ Leukemia ☐ Other ____________________ ☐ Unknown

CRF: SURVIVAL & QUALITY OF LIFE

Patient Status	
Alive?	◯ Yes ◯ No ◯ Unknown
Date of Death	______ / _______ / _______
Cause(s) of death	☐ Primary immunodeficiency ☐ Malignancy ☐ Infection ☐ Other Cause ________________ ☐ Unknown

Disability	
Patient has significant disability	◯ Yes ◯ No ◯ Unknown
Age began	__________________ years __________________ months
Conditions	_______________________________ _______________________________ _______________________________ _______________________________ _______________________________

Karnofsky Performance Status Scale Definitions Rating (%) – **Patient is 18 or older**		
Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead
Karnofsky Score:	___________________	

Lansky Performance Status Scale (%) – **Patient is under 18**	
100	Fully active, normal
90	Minor restrictions with strenuous physical activity.
80	Active, but gets tired more quickly
70	Both greater restriction of, and less time spent in, active play
60	Up and around, but minimal active play; keeps busy with quieter activities
50	Lying around much of the day, but gets dressed; no active play; participates in all quiet play and activities
40	Mostly in bed; participates in quiet activities
30	Stuck in bed; needs help even for quiet play.
20	Often sleeping; play is entirely limited to very passive activities
10	Does not play nor get out of bed
0	Unresponsive
Lansky Score:	____________________

CRF: CORE LABORATORY TEST RESULTS

Complete Blood Count				
Date of Test	______ / _______ / _______			
WBC	____________	THOU/uL		
Platelets	____________	THOU/uL		
RBC	____________	MILL/uL		
Hgb	____________	g/dL		
Lymphocytes	____________	%	____________	/uL
PMN	____________	%	____________	/uL
Eosinophils	____________	%	____________	/uL
Basophils	____________	%	____________	/uL
Monocytes	____________	%	____________	/uL

Lymphocyte Phenotype				
Date of Test	______ / _______ / _______			
Absolute Lymphocyte Count	____________	/uL		
CD3 T Cells	____________	%	____________	/uL
CD4 Helper T	____________	%	____________	/uL
CD8 Cytotoxic T	____________	%	____________	/uL
CD19 B Cells	____________	%	____________	/uL
CD20 B Cells	____________	%	____________	/uL
CD56/CD16 NK cells	____________	%	____________	/uL

CD4 Subset Panel					
Date of Test	______ / _______ / _______				
Naive CD4+ T-Cells	○ CD4+ CD45RA+ ○ CD4+ CCR7+ CD45RA+ ○ CD4+ CD27+ CD45RA+ ○ Other or unknown markers used	____________	%	____________	/uL
Total Memory CD4+ T cells	○ CD4+ CD45RO+ ○ CD4+ CD45RA- ○ Other or unknown markers used	____________	%	____________	/uL
Central Memory CD4+ T cells	○ CD4+ CCR7+ CD45RA- ○ CD4+ CCR7+ CD45RO+ ○ Other or unknown markers used	____________	%	____________	/uL
Effector Memory CD4+ T cells	○ CD4+ CCR7- CD45RA- ○ CD4+ CCR7- CD45RO+ ○ Other or unknown markers used	____________	%	____________	/uL

CD8 Subset Panel

Date of Test	______ / _______ / _______				
Naive CD8+ T-Cells	◯ CD8+ CD45RA+ ◯ CD8+ CCR7+ CD45RA+ ◯ CD8+ CD27+ CD45RA+ ◯ Other or unknown markers used	____________	%	____________	/uL
Total Memory CD8+ T cells	◯ CD8+ CD45RO+ ◯ CD8+ CD45RA- ◯ Other or unknown markers used	____________	%	____________	/uL
Central Memory CD8+ T cells	◯ CD8+ CCR7+ CD45RA- ◯ CD8+ CCR7+ CD45RO+ ◯ Other or unknown markers used	____________	%	____________	/uL
Effector Memory CD8+ T cells	◯ CD8+ CCR7- CD45RA- ◯ CD8+ CCR7- CD45RO+ ◯ Other or unknown markers used	____________	%	____________	/uL
"Senescent" CD8+ T cells	◯ CD8+ CD57+ ◯ Other or unknown markers used	____________	%	____________	/uL

Memory B Cell Phenotype

Date of Test	______ / _______ / _______	
	% of B Cells	**/uL**
CD27+ B Cells (Total Memory B)	________________	________________
CD27 + IgM + B Cells (IgM Memory B)	________________	________________
CD27 + IgD - B Cells (Switched Memory B)	________________	________________

Immunoglobulin Evaluation

Date of Test	______ / _______ / _______				
IgG	____________	mg/dL	**IgG1**	____________	mg/dL
IgA	____________	mg/dL	**IgG2**	____________	mg/dL
IgM	____________	mg/dL	**IgG3**	____________	mg/dL
IgE	____________	IU/mL	**IgG4**	____________	mg/dL
IgD	____________	mg/dL			

Vaccine Responses		
	Date of Test	**Response**
Diphtheria	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Tetanus	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
HIB Polysaccharide	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Protein Conjugated HIB	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Isohemagglutinin - Anti A	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Isohemagglutinin - Anti B	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Chicken Pox	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Measles	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
PHI X 174 or other neoantigen	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Mumps	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Rubella	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal

Unconjugated Pneumococcal Vaccine Response	
Unconjugated Vaccine Tested?	◯ Tested ◯ Not Tested
Date of Test	______ / _______ / _______
# of serotypes producing a protective level	_______________________ serotypes
# of serotypes TESTED	_______________________ serotypes
# of times vaccine administered	_______________________ times

Conjugated Pneumococcal Vaccine Response	
Conjugated Vaccine Tested?	◯ Tested ◯ Not Tested
Date of Test	______ / _______ / _______
# of serotypes producing a protective level **# of serotypes TESTED**	_______________________ _______________________
Vaccine Name	☐ Prevnar 7 (PCV7) ☐ Prevnar 13 (PCV13) ☐ Other ___________________ ☐ Unknown
# of times **PCV7** administered # of times **PCV13** administered # of times **Other** administered # of times **Unknown** administered	_______________________ _______________________ _______________________ _______________________

TRECS	
TRECS Tested?	◯ Tested ◯ Not Tested
Date of Test	______ / _______ / _______
Response	◯ Absent ◯ Low ◯ Normal

Lymphocyte Function		
	Date of Test	**Response**
PHA	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
ConA	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
PWM	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Anti-CD3	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Antigens - Tetanus	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Antigens – Diphtheria	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Antigens – Candida	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Alloantigen (MLC)	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
NK Cell Cytotoxicity	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal

Skin Testing		
	Date of Test	**Response**
Tetanus	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
Candida	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal

Complement Function		
	Date of Test	**Response**
CH50	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal
AH50	______ / _______ / _______	◯ Absent ◯ Low ◯ Normal

TCR-V Beta Repertoire Analysis		
	Date of Test	**Response**
TCR-V Beta	______ / _______ / _______	◯ Normal ◯ Skewed

Autoantibodies	
	Results
ANA greater than 1:180	◯ Yes ◯ No ◯ Unknown
Anti-neutrophil antibody	◯ Yes ◯ No ◯ Unknown
Anti-platelet antibody	◯ Yes ◯ No ◯ Unknown
Coombs positive (direct)	◯ Yes ◯ No ◯ Unknown

Other Autoantibodies	
	Results
__________________________________	◯ Present ◯ Not Present
__________________________________	◯ Present ◯ Not Present
__________________________________	◯ Present ◯ Not Present
__________________________________	◯ Present ◯ Not Present

CRF: MOLECULAR INFORMATION

Genetic Information		
Pattern of Inheritance	◯	Sporadic (no prior family history)
	◯	X-linked
	◯	Autosomal recessive
	◯	Ambiguous positive family history
	◯	Other ____________________
	◯	Unknown
Is this patient's PID linked to a gene mutation?	◯	Yes; PI is linked to gene
	◯	No; Gene not identified
	◯	Gene tested; no mutation found

Gene Mutation	
Gene	________________________________
Mutation Type	◯ Complex (hgvs/iscn)
	◯ Deletion
	◯ Deletion/Insertion (indel)
	◯ Duplication
	◯ Insertion
	◯ Inversion
	◯ Substitution
DNA Change	________________________________
Protein Change	________________________________
Zygosity	◯ Homozygous
	◯ Heterozygous
	◯ X-Linked Hemizygous
	◯ Unknown
Comments on how mutation was detected	________________________________

Gene	________________________________
Mutation Type	◯ Complex (hgvs/iscn)
	◯ Deletion
	◯ Deletion/Insertion (indel)
	◯ Duplication
	◯ Insertion
	◯ Inversion
	◯ Substitution
DNA Change	________________________________
Protein Change	________________________________
Zygosity	◯ Homozygous
	◯ Heterozygous
	◯ X-Linked Hemizygous
	◯ Unknown
Comments on how mutation was detected	________________________________

Gene	___________________________________
Mutation Type	◯ Complex (hgvs/iscn) ◯ Deletion ◯ Deletion/Insertion (indel) ◯ Duplication ◯ Insertion ◯ Inversion ◯ Substitution
DNA Change	___________________________________
Protein Change	___________________________________
Zygosity	◯ Homozygous ◯ Heterozygous ◯ X-Linked Hemizygous ◯ Unknown
Comments on how mutation was detected	___________________________________

Testing Done; Mutation not Found	
Mutation Not Found: Gene	___________________________________

Protein / Enzyme Expressed		
Protein	**Protein Expressed?**	**Tested by**
________________________________	◯ Yes ◯ No ◯ Unknown	◯ By Western ◯ By FACS ◯ Other __________________________
________________________________	◯ Yes ◯ No ◯ Unknown	◯ By Western ◯ By FACS ◯ Other __________________________
________________________________	◯ Yes ◯ No ◯ Unknown	◯ By Western ◯ By FACS ◯ Other __________________________
________________________________	◯ Yes ◯ No ◯ Unknown	◯ By Western ◯ By FACS ◯ Other __________________________
________________________________	◯ Yes ◯ No ◯ Unknown	◯ By Western ◯ By FACS ◯ Other __________________________
________________________________	◯ Yes ◯ No ◯ Unknown	◯ By Western ◯ By FACS ◯ Other __________________________