APPENDIX 5

Demographics for Research Participants

	Healthcare Provider	Parent Participants
	Participants	
<b>National Capital</b>	31	19
Area Total		
USUHS	6	15
WRAMC	8	2
NNMC	6	1
MGMC	11	1
Madigan AMC	28	35
NMC San Diego	24	24
Wright Patterson	17	15
AFMC		
TOTAL	100	93

# **Parents**

Active Duty Army	23
Active Duty Navy	12
Active Duty Marine Corps	3
Active Duty Air Force	18
Retired (all)	15
Active Duty, but branch unknown	15
Completely unknown service	7
Total	93

	<u>National</u>	<b>Madigan</b>	NMC San	<u>Wright</u>
	Capital Area	<b>AMC</b>	<u>Diego</u>	<u>Patterson</u>
				<u>AFMC</u>
Officer – Ret	0	1	0	1
Officer – Active	0	6	3	5
Duty				
Officer –	0	0	0	0
unknown				

<sup>\*</sup>Madigan AMC also has 1 senior enlisted

# **Healthcare Providers**

# Gender

	Males	Females	Total				
National Capital A	National Capital Area						
USUHS	5	1	6				
WRAMC	4	4	8				
NNMC	1	5	6				
MGMC	4	7	11				
National Capital	14	17	31				
Area Total							
Madigan AMC	18	10	28				
NMC San Diego	12	12	24				
Wright Patterson	7	10	17				
AFMC							
Total Healthcare	51	49	100				
Providers							

Specialties

	Nation	Madigan	NMC	Wright-	<u>TOTAL</u>
	<u>al</u>	<u>AMC</u>	San	Patterson	
	Capita		<u>Diego</u>	<u>AFMC</u>	
	1 Area		_		
General Pediatricians	4	2	7	3	16
Pediatric NICU Fellows	2				2
Pediatric Interns/Residents		9	9	8	26
Developmental Fellow		1			1
Medical Students			2		2
Family Medicine Physicians	3		1		4
Family Medicine Residents	9	3			12
Nurses, Care Coordinators, Case	8	3	3	4	18
Managers, Social Workers,					
Palliative Care Managers					
Psychologist	1				1
Pediatric Psychiatrist		1			1
Internal Medicine Physician	1				1
Pediatic Intensivist	1				1
Pediatric Cardiologist	1	1	1		3
Pediatric Neurologist		1			1
Developmental Pediatrician		2	1		3
Pediatric Oncologist	1	1			2
Pediatric Infectious Disease		1			1
Specialist					
Adolescent Medicine		1			1

Pediatric Endocrinologist		1		1	2
Pediatric Dysmorphologist		1			1
Pediatric Gastroenterologist				1	1
TOTAL	31	28	24	17	100

Ethnicity

nnicuy				I		
	White	African	<b>Pacific</b>	Native	Hispanic	Other
		American	Islander	American		
<b>National Capi</b>	tal Area					
USUHS						
WRAMC						
NNMC						
MGMC						
National						
Capital Area						
Total						
Madigan						
AMC						
NMC San	10	0	1	0	2	11
Diego						
Wright	15	0	0	0	0	1
Patterson						
AFMC						
Total	10	0	1	0	2	11
Healthcare						
<b>Providers</b>						

Specialtie<u>s</u>

NATIONAL	Overall:
CAPITAL	<ul> <li>7 Pediatricians or Pediatric Subspecialists</li> </ul>
AREA*	<ul> <li>2 Pediatric Residents or Fellows</li> </ul>
	<ul> <li>2 Family Medicine Physicians</li> </ul>
	<ul> <li>9 Family Medicine Residents</li> </ul>
	• 8 Nurses, Care Coordinators, Case Managers,
	Social Workers, Palliative Care Managers
	• 1 Psychologist
	• 1 Internal Medicine Physician
	Specifics:
	<ul> <li>Social Worker</li> </ul>
	<ul> <li>Pediatric Fellow</li> </ul>
	• Family Practice Residents (9-10)
	<ul> <li>Nurse Case Manager/Clinical Nurse</li> </ul>

	Specialist (2)
	<ul> <li>Clinical Nurse Specialist</li> </ul>
	<ul> <li>RN Pediatric Case Manager</li> </ul>
	<ul> <li>NICU staff nurse discharge planner</li> </ul>
	<ul> <li>Palliative Care Coordinator</li> </ul>
	• Family Medicine Physician (2)
	Internal Medicine
	Pediatric Cardiologist
Madigan AMC	Overall:
S	11 Pediatricians or Pediatric Subspecialists
	• 10 Pediatric Residents or Fellows
	3 Family Medicine Residents
	3 Nurse Practitioners, Nurse Case Mangers,
	Social Workers
	• 1 Psychiatrist
	1 1 Sychiatrist
	Specifics:
	Nurse Case Manager
	Nurse Practitioner
	<ul> <li>Dysmorphologist</li> </ul>
	Psychiatrist
	Clinical Social Worker
	• Pediatrician (3)
	Pediatric Neurologist
	Pediatric Cardiologist
	Developmental Pediatrician
	Oncologist
	<ul> <li>Infectious Disease Specialist</li> </ul>
	Adolescent Medicine
	Endocrinologist
	<ul> <li>Developmental Pediatric Fellow (1)</li> </ul>
	Pediatric Residents (9)
	• Family Medicine Residents (3)
NMC San Diego	Overall:
Title sun Biego	9 Pediatricians or Pediatric Subspecialists
	• 11 Pediatric Residents, Interns, or Students
	3 Nurse Case Mangers, Social Workers, or
	Clinic Coordinators
	1 Family Medicine Physician
	2 2 dames y 2.20010mile y 1113 bioletin
	Specifics:
	Nurse Case Manager
	Coordinator of Developmental Clinic
	NICU Social Worker

	• Pediatrician (7)			
	Pediatric Cardiologist			
	<ul> <li>Developmental Pediatrician</li> </ul>			
	Family Medicine			
	• Pediatric Residents (5)			
	• Pediatric Interns (4)			
	Medical Students (2)			
Wright Patterson	Specifics:			
AFMC	• Pediatric Case Manager (2)			
	• General Pediatrician (3)			
	Chief Pediatric Resident			
	Pediatric Clinical Nurse			
	Nurse Practitioner			
	Pediatric Gastroenterologist			
	Endocrinologist			
	Pediatric Residents (7)			

<sup>\*</sup>All healthcare provider interviews were grouped together for the National Capital Area so it is unknown which specialties came from which specific site within the National Capital Area.

# **Parent Participants**

# **Uniformed Services University**

Male Parents: 4 Female Parents: 11 Total: 15

Age of Child	<u>Diagnosis</u>	Military Service	State of
			Residence
8	Oligohydroamniosis	Army – Retired	Minnesota
14	Leukemia	Air Force – Retired	MD
Died at 15	Heart condition	Navy	VA
11 (died later	Cerebral Palsy,	Marine	VA
at 12)	Quadriplegic		
Died at 14	Cerebral Palsy,	Army – Retired	MD
	Quadriplegic	_	
15	Rhett's Syndrome	Air Force – Retired (2	MD
		parents)	
14	Cerebral Palsy	Air Force	MD
7	Leukodystrophy (possibly)	Air Force	MD
?	Leukemia	Army	MD
Died at 20	Cystic Fibrosis	Army	VA
Died at 14	Brain cancer	Navy	VA
18	Cerebral Palsy	Army Active Duty (2	MD
		parents)	

## **Walter Reed Army Medical Center**

Male Parent: 0 Female Parent: 2 Total: 2

Age of Child	<u>Diagnosis</u>	Military Service	<b>State of Residence</b>
4	DiGeorge Syndrome	Army	MD
17	Cerebral Palsy	Army	MD

## **National Naval Medical Center**

Male Parent: 0 Female Parent: 1 Total: 1

Age of Child	<u>Diagnosis</u>	Military Service	<b>State of Residence</b>
14 mo	Hypoplastic Lung	?	MD

## **Malcom Grow Air Force Medical Center**

Male Parent: 0 Female Parent: 1 Total: 1

Age of Child	<u>Diagnosis</u>	Military Service	State of Residence
Died at 1 or 2	Seizure disorder	Air Force	MD

Madigan Army Medical Center

Male Parents: 8 Female Parents: 27 Total: 35

Child   Italamic AVM with a dilation of the vena Galen   Active Duty Army (husband was Army too but got out)   wife of Active Duty husband (both husband and wife participated)   wife of Active Duty husband (both husband and wife participated)   wife of Active Duty Army (husband doth wife participated)   wife of Active Duty Army (both husband and wife participated)   wife of Active Duty Army (both husband and wife participated)   wife of Active Duty Army (both husband and wife participated)   wife who is a cancer too   wife wife wife wife wife wife wife wife	maie Pa	arents: 8 Female Parents: 27 Total: 35		_
(over son with cerebral palsy, he's a twin with cerebral palsy, brain husband and wife participated wife for Active Duty husband wife participated (both husband and wife participated) (both husband and wife participated) (ex-husband Active Duty Air Force and retiring soon but kids will be covered under his new wife who is still Active Duty arm will be covered under his new wife who is still Active Duty, came from Ft. Hood husband is Active Duty Army husband is Active Duty Army husband is Active Duty army she gets privileges and husband Active Duty enlisted Army, PV1 husband is retired Army she gets privileges and husband Active Duty enlisted Army, PV1 husband and wife participated) husband participated) husband participated) husband and wife participated) husband is Active Duty enlisted Air Force disorder husband and wife participated) husband is Active Duty enlisted husband participated) husband is Active Duty enlisted husband and wife participated) husband is Active Duty Navy enlisted husband Active Duty Army officer, her son is sick (child is participant's grandson) husband Active Duty Army		<u>Diagnosis</u>	Military Service	<b>Ethnicity</b>
Son with cerebral palsy, he's a twin   wife of Active Duty husband (both husband and wife participated)   ex-husband Active Duty Air Force and retiring soon but kids will be covered under his new wife who is still Active Duty, came from Ft. Hood   husband is Active Duty, came from Ft. Hood   husband is Active Duty, came from Ft. Hood   husband is Active Duty Army   husband Active Duty enlisted Army, PVI   Active Duty enlisted Army, PVI   Active Duty Army officer (wife and husband participated)   husband is Active Duty enlisted Army, PVI   Active Duty Army officer (husband and wife participated)   husband is Active Duty Navy enlisted   husband Active Duty Navy enlisted   husband Active Duty Officer, her son is sick (child is participant's grandson)   husband Active Duty Army	11	thalamic AVM with a dilation of	Active Duty Army (husband was	
twin (both husband and wife participated)  diagnosed with muscular dystrophy at 2, has bad scoliosis  diagnosed with muscular dystrophy at 2, has bad scoliosis  ex-husband Active Duty Air Force and retiring soon but kids will be covered under his new wife who is still Active Duty  hemorrhaging, prenatal strokes, alopecia universalis (hair loss disease)  Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical bilindness  diagnosed with severe cerebral palsy at 3 mo old gets privileges  diagnosed with Duchenne muscular dystrophy at 5 yrs old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  sovere cerebral palsy, seizure disorder  Rhett syndrome Active Duty Army officer (wife and husband participated)  Active Duty Army officer (wife and husband participated)  Active Duty Army officer (wife is German)  Active Duty Army officer (wife and husband participated)  Active Duty Army officer (husband and wife participated)  Rhett syndrome Active Duty Army officer (husband and wife participated)  Rhett syndrome Active Duty Army officer (husband and wife participated)  Reserve cerebral palsy, Quadriplegic husband Active Duty Navy enlisted  baby shake syndrome, seizures daughter is Active Duty officer, her son is sick (child is participant's grandson)  cerebral palsy, brain husband Active Duty Army		the vena Galen	Army too but got out)	
twin (both husband and wife participated)  diagnosed with muscular dystrophy at 2, has bad scoliosis  diagnosed with muscular dystrophy at 2, has bad scoliosis  an eonatal seizures, sub-arachnoid hemorrhaging, prenatal strokes, alopecia universalis (hair loss disease)  Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical bilindness  diagnosed with buchenne muscular dystrophy at 5 yrs old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  sort severe cerebral palsy, seizure disorder  Rhett syndrome  Rhett syndrome  Restriction failure to thrive, a seizure disorder  Active Duty enlisted Air Force and husband Active Duty enlisted Army, PV1  Active Duty Army officer (wife and husband participated)  Active Duty Army officer (wife and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty Army officer (musband and wife participated)  Rhett syndrome  Active Duty army officer (musband and wife participated)  Robaby shake syndrome, seizures  daughter is Active Duty officer, her son is sick (child is participant's grandson)  husband Active Duty Army  Active Duty Navy enlisted  husband active Duty Navy enlisted  husband is Active Duty officer, her son is sick (child is participant's grandson)	(over	son with cerebral palsy, he's a	wife of Active Duty husband	
diagnosed with muscular dystrophy at 2, has bad scoliosis  learned participated)  ex-husband Active Duty Air Force and retiring soon but kids will be covered under his new wife who is still Active Duty  lusband is Active Duty, came from Ft. Hood  lusband is Active Duty, came from Ft. Hood  lusband is Active Duty Army  lusband is retired Army she gets privileges  Active Duty enlisted Air Force  lusband Active Duty enlisted Army, PV1  lusband Active Duty army officer (wife and husband participated)  lusband is Active Duty enlisted Air Force  lusband Active Duty Army officer (husband and wife participated)  Active Duty Army officer (husband and wife participated)  Rhett syndrome  Active Duty Army officer (husband and wife participated)  Rhett syndrome  Active Duty Army officer (husband and wife participated)  Active Duty Army officer (husband and wife participated)  lusband Active Duty Participated)  lusband Active Duty Navy enlisted  aughter is Active Duty officer, her son is sick (child is participant's grandson)  lusband Active Duty Army lusted  lusband Active Duty Army lusted  lusband Active Duty Officer, her son is sick (child is participant's grandson)  lusband Active Duty Army lusted	2)	twin	•	
diagnosed with muscular dystrophy at 2, has bad scoliosis wife who is still Active Duty Air Force and retiring soon but kids will be covered under his new wife who is still Active Duty, came from Ft. Hood hemorrhaging, prenatal strokes, alopecia universalis (hair loss disease)  Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical bilindness  diagnosed with Duchenne muscular dystrophy at 5 yrs old Had eye surgery for strabismus at 3 mo; seizures started at 6 mo hoth with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  severe cerebral palsy, seizure disorder Rhett syndrome Active Duty enlisted Air Force (husband and wife participated)  Rhett syndrome Active Duty Army officer (husband and wife participated)  leukemia husband is Active Duty officer, her son is sick (child is participant's grandson)  husband Active Duty Army  ex-husband is Active Duty Army  husband is Active Duty Army officer (her son is sick (child is participant's grandson)  husband Active Duty Army  ex-husband and wife participated of the son is sick (child is participant's grandson)	,		participated)	
dystrophy at 2, has bad scoliosis will be covered under his new wife who is still Active Duty  4	13	diagnosed with muscular	ex-husband Active Duty Air	
wife who is still Active Duty  1 neonatal seizures, sub-arachnoid hemorrhaging, prenatal strokes, alopecia universalis (hair loss disease)  2 Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical bilindness  2 diagnosed with severe cerebral palsy at 3 mo old gets privileges  3 diagnosed with Duchenne muscular dystrophy at 5 yrs old  14 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo and the ferciency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  The first who is still Active Duty Army officer (husband and wife participated)  17: 9 leukemia  18 cerebral palsy, Quadriplegic husband Active Duty enlisted  19 leukemia  10 leukemia  11 leukemia  12 leukemia  13 baby shake syndrome, seizures  24 diagnosed before birth. bilateral pushand is Active Duty officer, her son is sick (child is participant's grandson)  25 levere cerebral palsy, brain  26 lusband and wife Duty officer, her son is sick (child is participant's grandson)			Force and retiring soon but kids	
husband is Active Duty, came from Ft. Hood  loganosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical bilindness  diagnosed with Severe cerebral palsy at 3 mo old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  severe cerebral palsy, seizure disorder  Rhett syndrome  Rhett syndrome  Palsy at Active Duty enlisted Air Force wife is German  Active Duty Army officer (wife and husband participated)  Active Duty Army officer wife is German  Active Duty Army officer wife is Active Duty enlisted husband is Active Duty Navy enlisted  Busband Active Duty officer, her son is sick (child is participant's grandson)  Revere cerebral palsy, brain husband Active Duty Army			will be covered under his new	
hemorrhaging, prenatal strokes, alopecia universalis (hair loss disease)  4 Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  The thood  husband is Active Duty Army officer (wife and husband participated)  Active Duty enlisted Air Force wife and husband participated)  Active Duty enlisted Air Force disorder  Active Duty enlisted Air Force disorder  Active Duty enlisted Air Force disorder  Active Duty army officer (wife and husband and wife participated)  Pactive Duty Army officer (husband and wife participated)  Rhett syndrome  Active Duty Army officer (husband and wife participated)  Pactive Duty Navy enlisted  baby shake syndrome, seizures  diagnose with severe cerebral palsy, brain  husband Active Duty Navy enlisted  husband Active Duty Navy enlisted			wife who is still Active Duty	
alopecia universalis (hair loss disease)  4 Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old gets privileges  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  5 Rhett syndrome  6 Leukemia  8 cerebral palsy, Quadriplegic  7 baby shake syndrome, seizures  alope buty Army officer (husband and wife participated)  Patient Potential	4	neonatal seizures, sub-arachnoid	husband is Active Duty, came	
disease)  Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  diagnosed with severe cerebral palsy at 3 mo old gets privileges  diagnosed with Duchenne muscular dystrophy at 5 yrs old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  Tr; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  severe cerebral palsy, seizure disorder  Rhett syndrome  Rhett syndrome  Rhett syndrome  Bushand is Active Duty Army officer (wife and husband participated)  Active Duty army officer (wife and husband participated)  Active Duty Army officer (husband and wife participated)  Reman  Active Duty Army officer (husband and wife participated)  Bushand is Active Duty Paly officer (husband and wife participated)  Active Duty Army officer (husband and wife participated)  Bushand is Active Duty Paly officer (husband and wife participated)  Active Duty Army officer (husband and wife participated)  Bushand Active Duty Navy enlisted  Active Duty Navy enlisted  Active Duty Navy enlisted  Active Duty Navy enlisted  Bushand Active Duty Officer, her son is sick (child is participant's grandson)  Severe cerebral palsy, brain  Bushand Active Duty Army		hemorrhaging, prenatal strokes,	from Ft. Hood	
Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  diagnosed with severe cerebral palsy at 3 mo old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo deficiency (x-linked hyper IgM); oldest son has cancer too  Rhett syndrome  Rhett syndrome  Bushand is Active Duty Army she gets privileges  Active Duty enlisted Air Force dand husband participated)  Active Duty Army officer (wife and husband participated)  Active Duty enlisted Air Force wife and husband participated)  Active Duty army officer (wife and husband participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband and wife participated)  Active Duty Army officer (wife and husband Active Duty Navy enlisted husband Active Duty Navy enlisted)  Active Duty Army officer (wife and husband Active Duty Navy enlisted)  Active Duty Army officer (wife and husband Active Duty Navy enlisted)  Active Duty Army officer (wife and husband Active Duty Officer, her son is sick (child is participant's grandson)  Active Duty Army		alopecia universalis (hair loss		
periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old gets privileges  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome Active Duty enlisted Air Force wife is German  5 Rhett syndrome Active Duty enlisted Air Force wife is German  6 Active Duty army officer (wife and husband participated)  7 Leukemia husband is Active Duty enlisted husband and wife participated)  8 cerebral palsy, Quadriplegic husband and wife participated husband Active Duty Navy enlisted  8 cerebral palsy, Quadriplegic daughter is Active Duty officer, her son is sick (child is participant's grandson)  9 severe cerebral palsy, brain husband Active Duty Army		disease)		
heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  Rhett syndrome  1 leukemia	4	Diagnosed before birth. bilateral	husband is Active Duty Army	
microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old gets privileges  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  Rhett syndrome  Active Duty army officer (wife and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty army officer (wife and husband participated)  Active Duty army officer (wife and husband participated)  Active Duty army officer (husband and wife participated)  husband is Active Duty enlisted  husband is Active Duty enlisted  husband Active Duty Navy enlisted  daughter is Active Duty officer, her son is sick (child is participant's grandson)  ? severe cerebral palsy, brain husband Active Duty Army		periventricular nodular		
gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old gets privileges  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  Rhett syndrome  7 leukemia  8 cerebral palsy, Quadriplegic  9 baby shake syndrome, seizures  4 cative Duty enlisted Air Force wife is disorder  Active Duty Army officer (wife and husband and wife participated)  9 leukemia  10 husband and wife participated husband and wife participated husband and Active Duty enlisted  11 husband Active Duty Navy enlisted  12 daughter is Active Duty officer, her son is sick (child is participant's grandson)  13 husband Active Duty officer, her son is sick (child is participant's grandson)  14 husband Active Duty officer, her son is sick (child is participant's grandson)		heterotopia, lissencephaly,		
restriction, failure to thrive, a seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old gets privileges  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  The syndrome Active Duty enlisted Air Force wife is German  5 Rhett syndrome  1 leukemia  8 cerebral palsy, Quadriplegic  1 baby shake syndrome, seizures  4 daughter is Active Duty officer, her son is sick (child is participant's grandson)  9 severe cerebral palsy, brain  1 busband Active Duty Army  1 baby Army  1 baby Shake syndrome, seizures  1 baby Shake Syndrome, seizures  2 severe cerebral palsy, brain  2 baby Shake Syndrome, seizures  3 severe cerebral palsy, brain		microcephaly with simplified		
seizure disorder, cortical blindness  20 diagnosed with severe cerebral palsy at 3 mo old  8 diagnosed with Duchenne muscular dystrophy at 5 yrs old  16 Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  The the tyndrome  Active Duty enlisted Air Force wife and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty army officer (wife and husband participated)  Active Duty Army officer wife is German  Active Duty Army officer wife is German  Active Duty Army officer wife is German  Active Duty Army officer daughter is Active Duty enlisted  Authority Duty Participated wife is German  Active Duty Army officer wife is German  Active Duty Navy enlisted  Authority Duty Army officer wife is German  Active Duty Army officer wife is German  Active Duty Navy enlisted  Authority Duty Army officer wife is German  Active Duty Navy enlisted  Aughter is Active Duty officer, her son is sick (child is participant's grandson)  Providence Active Duty Army		gyri, intrauterine growth		
blindness  diagnosed with severe cerebral palsy at 3 mo old  diagnosed with Duchenne muscular dystrophy at 5 yrs old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  severe cerebral palsy, seizure disorder  Rhett syndrome  Rhett syndrome  Pleukemia  Retered and husband is retired Army she gets privileges  Active Duty enlisted Air Force wife and husband participated)  Active Duty Army officer (wife and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty Army officer (husband and wife participated)  Rhett syndrome  Active Duty Army officer (husband and wife participated)  husband is Active Duty enlisted  husband Active Duty Navy enlisted  baby shake syndrome, seizures  daughter is Active Duty officer, her son is sick (child is participant's grandson)  severe cerebral palsy, brain  husband Active Duty Army		restriction, failure to thrive, a		
diagnosed with severe cerebral palsy at 3 mo old gets privileges  Active Duty enlisted Air Force  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  Rhett syndrome  Rhett syndrome  Belukemia  Cerebral palsy, Quadriplegic  baby shake syndrome, seizures  baby shake syndrome, seizures  cex-husband is retired Army she gets privileges  Active Duty enlisted Air Force  Army, PV1  Active Duty Army officer (wife and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty Army officer  (husband and wife participated)  Pushand Active Duty enlisted  Active Duty enlisted  Active Duty enlisted  Active Duty enlisted  Active Duty officer  (husband Active Duty enlisted  Active Duty officer  (husband Active Duty Navy enlisted  Active Duty officer, her son is sick (child is participant's grandson)  Revere cerebral palsy, brain  Active Duty Army		seizure disorder, cortical		
palsy at 3 mo old gets privileges  diagnosed with Duchenne muscular dystrophy at 5 yrs old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  husband Active Duty enlisted Army, PV1  Active Duty Army officer (wife and husband participated)  severe cerebral palsy, seizure disorder  Rhett syndrome  Rhett syndrome  Publication of the syndrome and th		blindness		
diagnosed with Duchenne muscular dystrophy at 5 yrs old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  Tr; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  severe cerebral palsy, seizure disorder  Rhett syndrome  Rhett syndrome  Reiedman  Active Duty enlisted Army, PV1  Active Duty Army officer (wife and husband participated)  Active Duty enlisted Air Force Wife is German  Active Duty Army officer (husband and wife participated)  Rubernan  Reiedman  Busband is Active Duty enlisted  Ausband is Active Duty enlisted  Ausband Active Duty enlisted  Ausband Active Duty enlisted  Ausband Active Duty Navy enlisted  Ausband Active Duty officer, her son is sick (child is participant's grandson)  Severe cerebral palsy, brain  Active Duty Army  Active Duty officer, her son is sick (child is participant's grandson)	20	diagnosed with severe cerebral	ex-husband is retired Army she	
muscular dystrophy at 5 yrs old  Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  Army, PV1  Active Duty Army officer (wife and husband participated)  severe cerebral palsy, seizure disorder  Rhett syndrome  Rhett syndrome  Publication  Reflex to the deficiency (x-linked hyper IgM); oldest son has cancer too  Active Duty enlisted Air Force wife is German  Active Duty Army officer (husband and wife participated)  Reflex to the deficiency (x-linked hyper IgM); and husband participated)  Reflex to the deficiency (x-linked hyper IgM); and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty Army officer (husband and wife participated)  husband is Active Duty enlisted  husband Active Duty Navy enlisted  daughter is Active Duty officer, her son is sick (child is participant's grandson)  severe cerebral palsy, brain  husband Active Duty Army				
Had eye surgery for strabismus at 3 mo; seizures started at 6 mo  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  Rhett syndrome  Pleukemia  Repertation  Active Duty Army officer (wife and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty Army officer (husband and wife participated)  Pleukemia  Repertation  Active Duty Army officer (husband and wife participated)  Active Duty enlisted  Active Duty Army officer (husband and wife participated)  Active Duty Army officer (wife and husband Active Duty officer, her son is sick (child is participant's grandson)  Active Duty Army officer (wife and husband Active Duty officer, her son is sick (child is participant's grandson)  Active Duty Army officer (wife and husband Active Duty Officer, her son is sick (child is participant's grandson)	8		Active Duty enlisted Air Force	
3 mo; seizures started at 6 mo Army, PV1  17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome Active Duty enlisted Air Force wife is German  5 Rhett syndrome Active Duty Army officer (husband and wife participated)  7 leukemia				
17; 9 both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too  3 severe cerebral palsy, seizure disorder  5 Rhett syndrome    Part	16	Had eye surgery for strabismus at	•	
deficiency (x-linked hyper IgM); oldest son has cancer too  severe cerebral palsy, seizure disorder  Rhett syndrome  leukemia  leukemia  cerebral palsy, Quadriplegic  baby shake syndrome, seizures  deficiency (x-linked hyper IgM); and husband participated)  Active Duty enlisted Air Force wife is German  Active Duty Army officer (husband and wife participated)  husband is Active Duty enlisted  husband Active Duty Navy enlisted  daughter is Active Duty officer, her son is sick (child is participant's grandson)  severe cerebral palsy, brain  husband Active Duty Army		3 mo; seizures started at 6 mo	Army, PV1	
oldest son has cancer too  severe cerebral palsy, seizure disorder  Rhett syndrome  Cerman  Active Duty enlisted Air Force wife is German  Active Duty Army officer (husband and wife participated)  leukemia  husband is Active Duty enlisted  cerebral palsy, Quadriplegic  husband Active Duty Navy enlisted  baby shake syndrome, seizures  daughter is Active Duty officer, her son is sick (child is participant's grandson)  severe cerebral palsy, brain  husband Active Duty Army	17; 9	both with genetic immune	Active Duty Army officer (wife	
3 severe cerebral palsy, seizure disorder  5 Rhett syndrome  6 leukemia  7 baby shake syndrome, seizures		deficiency (x-linked hyper IgM);	and husband participated)	
disorder  Rhett syndrome Active Duty Army officer (husband and wife participated)  leukemia husband is Active Duty enlisted  cerebral palsy, Quadriplegic husband Active Duty Navy enlisted  baby shake syndrome, seizures baby shake syndrome, seizures daughter is Active Duty officer, her son is sick (child is participant's grandson)  severe cerebral palsy, brain husband Active Duty Army		oldest son has cancer too		
Rhett syndrome Active Duty Army officer (husband and wife participated)  leukemia husband is Active Duty enlisted  cerebral palsy, Quadriplegic husband Active Duty Navy enlisted  baby shake syndrome, seizures daughter is Active Duty officer, her son is sick (child is participant's grandson)  severe cerebral palsy, brain husband Active Duty Army	3		Active Duty enlisted Air Force	wife is
(husband and wife participated)  ? leukemia husband is Active Duty enlisted  8 cerebral palsy, Quadriplegic husband Active Duty Navy enlisted  7 baby shake syndrome, seizures daughter is Active Duty officer, her son is sick (child is participant's grandson)  ? severe cerebral palsy, brain husband Active Duty Army				German
<ul> <li>leukemia</li> <li>cerebral palsy, Quadriplegic</li> <li>baby shake syndrome, seizures</li> <li>baby shake syndrome, seizures</li> <li>participant's grandson</li> <li>severe cerebral palsy, brain</li> <li>husband Active Duty Navy enlisted</li> <li>daughter is Active Duty officer, her son is sick (child is participant's grandson)</li> <li>severe cerebral palsy, brain</li> </ul>	5	Rhett syndrome	, ,	
8 cerebral palsy, Quadriplegic husband Active Duty Navy enlisted 7 baby shake syndrome, seizures daughter is Active Duty officer, her son is sick (child is participant's grandson) ? severe cerebral palsy, brain husband Active Duty Army				
enlisted  7 baby shake syndrome, seizures daughter is Active Duty officer, her son is sick (child is participant's grandson)  ? severe cerebral palsy, brain husband Active Duty Army				
7 baby shake syndrome, seizures daughter is Active Duty officer, her son is sick (child is participant's grandson) ? severe cerebral palsy, brain husband Active Duty Army	8	cerebral palsy, Quadriplegic	husband Active Duty Navy	
her son is sick (child is participant's grandson) ? severe cerebral palsy, brain husband Active Duty Army				
participant's grandson) ? severe cerebral palsy, brain husband Active Duty Army	7	baby shake syndrome, seizures		
? severe cerebral palsy, brain husband Active Duty Army				
, , , , , , , , , , , , , , , , , , ,				
damage, needs risky heart surgery enlisted	?	± • •	1	
		damage, needs risky heart surgery	enlisted	

	seizures and cerebral palsy	y, asa assy
5	cyst on the corpus collosum, has	Army, active duty
6	in remission for ALL, diagnosed at 3	husband is E6 (Army? Stationed at Ft Lewis)
at 7		retiring in 3 years
Died	astrocytoma brain tumor	husband is Active Duty in Navy,
4	4.5 mo preemie, severe Cerebral Palsy, non-verbal, blind	Husband Active Duty
2	Joubert Syndrome (basically poor muscle tone)	Husband Active Duty (Army?)
5	diagnosed with leukemia at 3 yrs old, it has reached to his spinal cord and brain	Active Duty E6 Army
2	hydroencephaly	husband Active Duty E3 Air Force
4	Rhett Syndrome, seizures	Husband is 0-3, mom is a nursing student (husband and wife participated),
7	diagnosed with infantile spasms at 4 mo, has cerebral palsy	husband Active Duty
21 mo	born without an anus and stomach exploded b/c of it, has pulmonary stenosis, slight cerebral palsy	husband Active Duty
17	cerebral palsy	husband Active Duty, has been away from home for military since 1999
4	congenital heart defect, discovered at 20 weeks, has had several open-heart surgeries	husband Active Duty Army warrant officer, she is a nurse
32	cerebral palsy, severely mentally retarded	husband retired Army officer, retired after 27 yrs
?	leukemia, relapsed 4 months before finishing treatment	husband Army senior enlisted, retiring in 1 week
1,2	hydrocephalous and severe delays (2 yr old)	been in 5 yrs (husband and wife participated)
7;2	wks, has has hydrocephalus with a shunt, chiari-II malformation which is where the brainstem gets pulled into the spinal cord cystic fibrosis (7 yr old);	hubby quit job to stay home with kids  Active Duty Army officer, has
3	diagnosed with spina bifida at 16	Active Duty enlisted Air Force,

Naval Medical Center, San Diego

\*This data is not as thorough, as transcripts have not yet been individually analyzed

Male Parent: 7 Female Parent: 17 Total: 24

Age of	Diagnosis	Military Service	Ethnicity
Child	Diagnosis	ivinitally service	<u> Zumercy</u>
?	Oldest autistic with behavioral	Husband Active Duty officer	white
•	problems; youngest (of 4) with		,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,
	autism and recent brain surgery		
?	multiple disabilities, ventilator-	Active Duty Marine Corps	African
	dependent	, i	American
?	1 with diabetes; 1 with asthma;	Husband Active Duty Navy	white
	youngest with undiagnosed	enlisted	
	collection of difficulties		
?	in remission from ALL	Active Duty but soon to retire	African
			American
2 sons,	Autism	Husband retired Navy	White
3 yrs			
old			
?	Tuberousclerosis	Former Active Duty (husband	White
		and wife there)	(both)
?	Rhett Syndrome	Active Duty	White
8	Sturgis Webber Syndrome	Active Duty	African
			American
2	Med-evaced from Triplet to	Active Duty	African
	Bethesda, aspirated, pneumonia,		American
	reflux		
3	Autism	Active Duty Navy officer	White
7 mo	Preemie needing oxygen and G-tube, failure to thrive	Active Duty Navy enlisted	Filipino
3	JMAL (?) a rare type of	?	Other
	leukemia; in remission but		
	relapse is common		
?	Nephritic syndrome, kidney	?	African
	failure, multiple medical		American
	problems		
5	Encephalitis that recurred, non-	Active Duty Navy enlisted	Filipino
	responsive to sight, touch,		
0	sound	TT 1 1	A.C.:
?	Preemie, G-tube, trach that was	Husband in Army reserves,	African American
	removed, born with grade 4	was in Navy	American
	bleed, coded 3 times at house,		
?	now doing better Two children with autism	Recently retired	Hienonia
*	Autism	Husband Active Duty	Hispanic ?
About	Cerebral Palsy	Active Duty Navy enlisted;	White
	Cerebrai Faisy	1	willte
5	,	single mother	

3	Metabolic storage disease	Active Duty Navy	White
17	Cerebral Palsy	Husband Active Duty Navy,	White
		nearing retirement	
20	Brain aneurism at 14 improving	Active Duty Marine Corps	White
	slowly		
*	Diabetes	?	White
?	?	Husband Active Duty officer;	African
		at Camp Pendleton	American

<sup>\*</sup>Said very little, doesn't fit Himelstein descriptions

<u>Wright Patterson Air Force Medical Center</u>
\*This data is not as thorough, as transcripts have not yet been individually analyzed

Female Parent: 2 Male Parent: 13 Total: 15

Age of	<u>Diagnosis</u>	Military Service	<b>Ethnicity</b>
Child			<u></u>
?	Anoplastic Wilms Tumor	Husband Active Duty Air	White
	1	Force intelligence officer	
6	Noonan's and Crohn's Disease	Husband Active Duty Air	White
		Force executive officer	
8	Spastic Quadriplegia	Husband Active Duty Air	White
		Force enlisted	
13	MMA (methylmionic	Husband retired Air Force	White
	academia)	(was officer at end of career)	
3	Chromoso micro-deletion on	Active Duty enlisted Air Force	White
	chromosome 9		
6	Asthma, nut allergy, didn't fit	Husband Active Duty Air	White
		Force?	
18 mo	Congenital Myopathy	Husband Active Duty Air	White
	(suspected	Force enlisted Senior Airman	
	multiminicort/congential		
	myopathy hypotonia)		
6	Crouzan's Disease and	Husband Active Duty officer	White
	Turner's Syndrome		
9	Cerebral Palsy	Husband retired Air Force	White
21 mo	?	Active Duty Air Force	White
4	Cerebral Palsy and Seizure	Husband Active Duty Air	White
	Disorder	Force officer (Lt Col or Major)	
4;2	Reflux as infant; Cerebral	Husband Active Duty Air	White (both
	Palsy	Force non-commissioned	parents
		officer (?)	there)
18;	Ataxia-Telangectasia (both	Husband retired Air Force	White (both
other	children)		parents
died 2 yrs			there)
ago at 17			