

## APPENDIX 5

### *Demographics for Research Participants*

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

### Parents

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

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

\*Madigan AMC also has 1 senior enlisted

## Healthcare Providers

### *Gender*

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

### *Specialties*

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

Pediatric Endocrinologist		1		1	2
Pediatric Dysmorphologist		1			1
Pediatric Gastroenterologist				1	1
<b>TOTAL</b>	<b>31</b>	<b>28</b>	<b>24</b>	<b>17</b>	<b>100</b>

**Ethnicity**

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

**Specialties**

<b>NATIONAL CAPITAL AREA*</b>	<p><u>Overall:</u></p> <ul style="list-style-type: none"> <li>• 7 Pediatricians or Pediatric Subspecialists</li> <li>• 2 Pediatric Residents or Fellows</li> <li>• 2 Family Medicine Physicians</li> <li>• 9 Family Medicine Residents</li> <li>• 8 Nurses, Care Coordinators, Case Managers, Social Workers, Palliative Care Managers</li> <li>• 1 Psychologist</li> <li>• 1 Internal Medicine Physician</li> </ul>
	<p><u>Specifics:</u></p> <ul style="list-style-type: none"> <li>• Social Worker</li> <li>• Pediatric Fellow</li> <li>• Family Practice Residents (9-10)</li> <li>• Nurse Case Manager/Clinical Nurse</li> </ul>

	<p>Specialist (2)</p> <ul style="list-style-type: none"> <li>• Clinical Nurse Specialist</li> <li>• RN Pediatric Case Manager</li> <li>• NICU staff nurse discharge planner</li> <li>• Palliative Care Coordinator</li> <li>• Family Medicine Physician (2)</li> <li>• Internal Medicine</li> <li>• Pediatric Cardiologist</li> </ul>
<b>Madigan AMC</b>	<p><u>Overall:</u></p> <ul style="list-style-type: none"> <li>• 11 Pediatricians or Pediatric Subspecialists</li> <li>• 10 Pediatric Residents or Fellows</li> <li>• 3 Family Medicine Residents</li> <li>• 3 Nurse Practitioners, Nurse Case Mangers, Social Workers</li> <li>• 1 Psychiatrist</li> </ul> <p><u>Specifics:</u></p> <ul style="list-style-type: none"> <li>• Nurse Case Manager</li> <li>• Nurse Practitioner</li> <li>• Dysmorphologist</li> <li>• Psychiatrist</li> <li>• Clinical Social Worker</li> <li>• Pediatrician (3)</li> <li>• Pediatric Neurologist</li> <li>• Pediatric Cardiologist</li> <li>• Developmental Pediatrician</li> <li>• Oncologist</li> <li>• Infectious Disease Specialist</li> <li>• Adolescent Medicine</li> <li>• Endocrinologist</li> <li>• Developmental Pediatric Fellow (1)</li> <li>• Pediatric Residents (9)</li> <li>• Family Medicine Residents (3)</li> </ul>
<b>NMC San Diego</b>	<p><u>Overall:</u></p> <ul style="list-style-type: none"> <li>• 9 Pediatricians or Pediatric Subspecialists</li> <li>• 11 Pediatric Residents, Interns, or Students</li> <li>• 3 Nurse Case Mangers, Social Workers, or Clinic Coordinators</li> <li>• 1 Family Medicine Physician</li> </ul> <p><u>Specifics:</u></p> <ul style="list-style-type: none"> <li>• Nurse Case Manager</li> <li>• Coordinator of Developmental Clinic</li> <li>• NICU Social Worker</li> </ul>

	<ul style="list-style-type: none"> <li>• Pediatrician (7)</li> <li>• Pediatric Cardiologist</li> <li>• Developmental Pediatrician</li> <li>• Family Medicine</li> <li>• Pediatric Residents (5)</li> <li>• Pediatric Interns (4)</li> <li>• Medical Students (2)</li> </ul>
<b>Wright Patterson AFMC</b>	<u>Specifics:</u> <ul style="list-style-type: none"> <li>• Pediatric Case Manager (2)</li> <li>• General Pediatrician (3)</li> <li>• Chief Pediatric Resident</li> <li>• Pediatric Clinical Nurse</li> <li>• Nurse Practitioner</li> <li>• Pediatric Gastroenterologist</li> <li>• Endocrinologist</li> <li>• Pediatric Residents (7)</li> </ul>

\*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

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>State of Residence</u>
8	Oligohydroamniosis	Army – Retired	Minnesota
14	Leukemia	Air Force – Retired	MD
Died at 15	Heart condition	Navy	VA
11 (died later at 12)	Cerebral Palsy, Quadriplegic	Marine	VA
Died at 14	Cerebral Palsy, Quadriplegic	Army – Retired	MD
15	Rhett’s Syndrome	Air Force – Retired (2 parents)	MD
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 parents)	MD

### Walter Reed Army Medical Center

Male Parent: 0      Female Parent: 2      Total: 2

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

### National Naval Medical Center

Male Parent: 0      Female Parent: 1      Total: 1

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

### Malcom Grow Air Force Medical Center

Male Parent: 0      Female Parent: 1      Total: 1

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

**Madigan Army Medical Center**

Male Parents: 8

Female Parents: 27

Total: 35

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>Ethnicity</u>
11	thalamic AVM with a dilation of the vena Galen	Active Duty Army (husband was Army too but got out)	
(over 2)	son with cerebral palsy, he's a twin	wife of Active Duty husband (both husband and wife participated)	
13	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	
4	neonatal seizures, sub-arachnoid hemorrhaging, prenatal strokes, alopecia universalis (hair loss disease)	husband is Active Duty, came from Ft. Hood	
4	Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness	husband is Active Duty Army	
20	diagnosed with severe cerebral palsy at 3 mo old	ex-husband is retired Army she gets privileges	
8	diagnosed with Duchenne muscular dystrophy at 5 yrs old	Active Duty enlisted Air Force	
16	Had eye surgery for strabismus at 3 mo; seizures started at 6 mo	husband Active Duty enlisted Army, PV1	
17; 9	both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too	Active Duty Army officer (wife and husband participated)	
3	severe cerebral palsy, seizure disorder	Active Duty enlisted Air Force	wife is German
5	Rhett syndrome	Active Duty Army officer (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 damage, needs risky heart surgery	husband Active Duty Army enlisted	

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



**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

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

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

\*Said very little, doesn't fit Himelstein descriptions

### **Wright Patterson Air Force Medical Center**

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

Male Parent: 13      Female Parent: 2      Total: 15

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