

Quality of life and self-esteem in Hemophilic children and adolescents

A thesis submitted for Fulfillment of the Ph. D. Degree in Childhood Studies - (special Needs)

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قسم الدراسات الطبية الأطفال والمراهقين جودة الحياة و تقدير الذات لدى الأطفال والمراهقين المصابين بالهيموفيليا

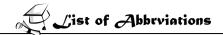
رسالة توطئة للحصول على درجة دكتوراه الفلسفة في دراسات الطفولة (ذوي احتياجات خاصة) قسم الدراسات الطبية للأطفال

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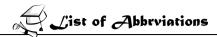


LIST OF ABBREVIATIONS

3DGA	Three-dimensional gait analysis	
AAV	Adeno-associated virus	
AAV2	AAV serotype 2	
ADHD	Attention-deficit/hyperactivity disorder	
aPCC	Activated prothrombin complex concentrate	
aPTT	Activated partial thromboplastin time	
AUC	Areas Under the Curve	
AVF	Arteriovenous Fistulae	
BDD	B domain-deleted	
BMI	Body mass index	
BU	Bethesda units	
CDC	Centers for Disease Control	
СНО	Chinese hamster ovary	
CVAD	Central venous access devices	
ECH	Extracranial hemorrhage	
F	Deficiency of plasma clotting factors	
FcRn	Neonatal Fc receptor	
FDA	Food and Drug Administration	
FVIII:C	FVIII coagulant	



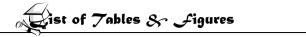
FXa	Activated Factor X	
HA	Hemophilia A	
НВ	Hemophilia B	
Ш	Hyperactivity-impulsivity	
НЮ	Health Insurance Organization	
HIV	Human immunodeficiency virus	
HRQL	Health-related quality of life	
HTC	Hemophilia treatment centers	
IAT	Implicit Association Test	
mAb216	An anti-FVIII mAb	
MRI	Magnetic resonance imaging	
NASPs	Non-anticoagulant sulfated polysaccharides	
NGOs	Nongovernmental organizations	
NN1731	NovoNordisk is developing a fast-acting rFVIIa	
	analog	
PD	Pharmacodynamic	
PEG	Polyethylene glycol	
PEGLip	Pegylated liposomes	
PEGylation	Chemical modification by PEG derivatives	
PICC	Peripherally inserted central catheter	
PK	Pharmacoki-netics	
-		



	V
PROs	patient-reported outcomes
PSA	polysialic acid
PTC124	PTC Therapeutics
QoL	Quality of life
ROM	Range of motion
SC	Self-complementary
SCAAV-PP5	Self-complementary AAV vector containing
	protein phosphatase 5 gene
SES	Socio-Economic Status
SNP	Single-nucleotide polymorphism
SS	Single-Stranded
TF	Tissue Factor
UDC	Universal Data Collection
VNTR	Variable number tandem repeat
VWF	Von Willebrand Factor
WISC	Wechsler Intelligence Scale for Children

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Psychiatric History

A. Personal History: Name: School grade: Age: Sex: religion: Father's → educational degree: **→** Job: → Age: Mother's → educational degree: **→** Job: **→** Age: Socio-economic status: Patient living with: Number of siblings: Order among siblings: Handedness: Address: Phone number: Email address: **B.** Complaint: Informants: Duration and frequency of complaint: Why they came for help? C. Developmental history: 1. Prenatal history: Emotional problems during pregnancy: Wanted and planned for child (or accidental):



Appendix

-	Parent wanted a boy or a girl:
-	Any medical condition:
-	Any obstetric condition:
-	Medications:
-	Radiation:
-	Others:
2.	Preinatal history:
-	Problems during labor:
-	CS or vaginal delivery:
-	Incubation: Prematurely:
-	Birth weight:
-	Color (prolonged jaundice – cyanosis):
-	Convulsions:
-	Congenital abnormalities:
-	Usual:
3.	Early developmental history (early weeks):
-	Sleep problems:
-	Feeding: allergies: problems:
	Mother attitude towards nursing:
	Breast or bottle feeding:
-	Difficult baby (irritable annoying) or easy baby:
-	Emotional status during infancy:
-	Temper tantrums:
D	. Present history:
1.	Start with the complaint
	o Onset
	o Course



Appendix

0	Previous consultations and ou	
	Then ask about the system rela	ated to the complaint
•		
	Ask about other systems:	
0	Motor:	
0		
0		
0	Abdomen	
4. A	Academic achievement:	
0	Grades in school:	
0		
0	Math achievements:	
5. A	Ask about behavioral disturba	nces as follows:
a) Eating disorders:	
-	Nausea & vomiting:	- Anorexia:
-	Pica:	- food refusal:
-	Bulimia:	- Rumination:
b) Sleep disorders:	
-	Insomnia:	- Nightmares:
-	Night terrors:	- somnambulism:
c) Speech disorders:	
-	Problems of speech:	
-	Articulation problem:	
_	Ask for visual and/or audito	ry problems:



Appendix

d) Sphincter control:
- Enuresis → primary or secondary
Diurnal or nocturnal
- Encopersis → primary or secondary
e) Social behavior:
- Aggressive: Timed:
- Tics: Submissive:
- Temper tantrums?
f) Conduct disorder:
- Stealing: Cruelty to animals:
- Lying: Violence:
- Fire setting: Oppositional:
- Truancy/run away: legal involvement:
g) Emotional problems:
1) Anxiety:
- Phobias: Panic:
- Fears: School refusal:
- Mutism: Obsessions:
2) Depression:
- Sad: Lonely:
- Change of behavior: