GENERAL INFORMATION

Today's Date:					
Child's Full Name:		Age:	Date	of Birth:	
Address:		City	State	Zip	
Name of person completing this form:					
Which X&Y Chromosome Variation (i.e. XXY, XYY, XXYY, XX	X) does your chil	d have?			
Child Was diagnosed: ☐ Prenatally ☐ before age 5 ☐	age 5-11	□age 12-18	□after age 18		
Approx. weight of child?	•	Approx. Height of	child?		
		. , ,			
CUF	RENT FAMILY	SITUATION			
Mother's Name:		Age:	Education:		
Relationship to Child: Natural Parent Step-Par	ent	☐Adoptive Parer	nt □Foster Parent		
Address:		City	State	Zip	
Home Phone: Cell Phone:		Work P	hone:		
Email Address:		Is ema	il a reliable way to c	:ontact you? □Ye	es □No
Father's Name:		Age:	Education:		
Relationship to Child: Natural Parent Step-Par	ent	☐Adoptive Parer	nt □Foster Parent		
Address:		City	State	Zip	
Home Phone: Cell Phone:			Work Phone:		
Email Address:		Is ema	il a reliable way to c	ontact you?	□Yes □No
With which parent(s) does the child live? □Both		☐Mother ☐Fathe	er	□Other,	
If Parents are separated or divorced, what year did this happen	n?	Who ha	as custody of this ch	nild?	
How often does the other parent see this child?					
Do any other adults live in the home ? \square Yes \square	No If yes, Nam	e, Age, Relationsh	nip:		
How many other children are living in the home? (Please indic	ate if step-brothe	rs/sisters or foster	brothers/sisters)		
Name and Age:					
Name and Age:					
Name and Age:					
Name and Age:					
Name and Age:					
Is child adopted? □Yes □No If yes, Does child know	v they are adopte	d? □Yes □No			
Age when child was first in home?		Date of Adoptio	n?		
Doctor's Name		Phon	ne		
Address:	City		State	Zip	

IN THE SPACE BELOW, PLEASE DISCUSS YOUR PRIMARY CONCERNS AND/OR WHAT YOU PRIMARILY WISH TO TALK ABOUT DURING OUR APPOINTMENT(S) IN OUR CLINIC:

BIRTH INFORMATION

Was infant born full term?	□Yes	□No	If premature, h	ow early?	If late, how overdue?	}
Birth weight?		Type of Delivery?	□Vaginal	□Cesarean	□Twins	
Describe any complications	during del	ivery:				
Infant's APGAR scores (if k	nown):		1 minute		5 minutes	
Did infant have:						
Breathing problems after bir	th?			□Yes	□No	
Did infant require:	Supplen	nental oxygen?		□Yes	□No	
	Breathin	g tube & Ventilator?		□Yes	□No	
Did infant need bilirubin ligh	ts (for jaur	idice/yellow skin)		□Yes	□No	
Did infant have seizures?				□Yes	□No	
Did infant have bleeding into	the brain	?		□Yes	□No	
Did physician express conce	ern about l	orain damage?		□Yes	□No	
Did infant require blood tran	sfusions?			□Yes	□No	
Did infant require X-rays/CT	scan/ultra	sounds?		□Yes	□No	
Did the infant require the NI	CU (Neona	atal Intensive Care U	Jnit)	□Yes	□No	
Previous pregnancies? Did mother receive prenatal Did mother have any medica Throats, Seizures, High Block	□Yes care durir al problem od Pressu	□No ng the pregnancy? s during or immediat re, Diabetes, Premat	If yes, number □Yes □Notely before/after ure labor, Anem	of pregnancies (Inclu Starting in wh the pregnancy? (Vag nia, Vaginal bleeding,	ding miscarriages, etc.) dich month? inal infections, Urinary Tract Infect Toxemia, Injuries, Emotional Prob	lems?)
Were any of the following us ☐ Medications. Please list: ☐Tobacco ☐Other (cocaine, amphetar		□Marijuana			□Alcohol	
	,	,	,	, -r		
Please list all other agencie: Child Protective Services, E			j. speech therap	y, OT, PT) involved v	vith your family (e.g. Regional Cen	ter, Healthy Start,

DEVELOPMENTAL HISTORY

Age whe	n child first rolled over?	on tim	e⊟late	□don't remember	
Age when child first sat alone?		on tim	e□late	□don't remember	
Age when child started walking independently?		□on tim	e□late	□don't remember	
ls your c	hild clumsy/uncoordinated? □Yes □No				
Can you	r child use a pencil/crayon? □Yes □No				
Can you	r child write his/her name? □Yes, at what age?		□No		
•	and does your child use for: Writing/drawing? □Right □L	.eft Eating? □F	– Right □Left		
	nild's first single words?	_		□don't remember	
	re his/her first words?				
	d spoke in 2 word-phrases?			□don't remember	
	d spoke in sentences?			□don't remember	
•	Id have difficulty with pronunciation/enunciation?			□No	
	d feed self?		e?		
	d dress self?	-			
		_	e?		
	d bathe self?	_	e?		
	d help with household chores?	_	e?		
	ld know home phone number and address?	_	e?		
Can child	d tell time accurately?	☐Yes, at what age	e?	_ □No	
Is child to	pilet trained?	☐Yes, at what ago	e	_ No	
	BEHAVIORAL/PS)	CHOLOGICAL INF	ORMATION		
Does you	ur child currently have, or had in the past, any of the followir	ng behaviors on a re	gular basis.(Check a	all that apply)	
	Temper tantrums/Oppositional behavior		Excessive worries/	fears	
	Impulsive	_	Doesn't like to be t		
	Hyperactive Short attention span/distractible		collars, belts, jewe	touching him (tags on his clothing,	
_	Repetitive Behaviors		Motor tics	,	
	Perseveration (conversation fixed on specific idea/topics)		Verbal tics		
	Aggressive/destructive behaviors		Resistance to char	nge in routine	
	Hand flapping		Cries often		
	Rocking/spinning		Anxiety		
	Nailbiting Picks/scratches body		Depression Panic Attacks		
	Poor coordination		Reclusive/isolated	hehavior	
	Poor eye contact		Moodiness/irritabili		
_	Isolated/withdrawn	_	Hallucinations (visi		
	Overly dependent/immature	_	Sleep problems/Ni		
	Shyness			-	

BEHAVIORAL/PSYCHOLOGICAL INFORMATION (continued)

Eating behavior					
□Normal □Picky, Eats too little	☐Eats too much				
Food Cravings? Yes If yes, what foods?	□No				
Problems chewing/swallowing? Yes	□No				
Other eating problems?					
Social behavior					
Does child make good eye contact?	□Yes	□No			
Does child like to play with other children?	□Yes	□No			
Does child have a fear of public places/crowds?	□Yes	□No			
Does child have poor social skills?	□Yes	□No			
Does child have friends?	□Yes	□No			
Does child have frequent conflicts with peers?	□Yes	□No			
· · · · · · · · · · · · · · · · · · ·					
	HOLOGICAL & DEVELOPM				
Has your child been previously evaluated for developmen	ital, behavioral, emotional, or	learning problems? □Yes	□No		
Who performed the previous treatments/evaluations/diagr		esults?			
Please include provider name, date performed and results	S				
☐Developmental Pediatrician					
□Neurologist					
□Psychologist					
□Psychiatrist					
☐Speech-Language Therapist					
☐ Occupational Therapist					
□ Physical Therapist					
□Other					
Has your child been previously been diagnosed with? (Ple					
☐ Attention Deficit Hyperactivity Disorder (ADHD)					
☐ Autism, Asperger's Syndrome, or Pervasive	Developmental Disorder (PD	D)			
☐ Speech delay					
☐ Developmental / Global delay					
☐ Depression					
☐ Anxiety Disorder					
☐ Sensory Integration Disorder					

MEDICAL PROBLEMS/EVALUATIONS

During this child's first 3 years, were any special problems noted in the following areas? □ Irritability □ Failure to thrive/poor growth & weight gain
□ Difficulty sleeping □ Colic □ Excessive crying
If yes to any above, please describe:
Does your child have other medical problems? Please check all that apply and explain, please include problems which have been treated in the past Ears? (Hearing problems, ear infections, etc.)
☐ Eyes? (Visual problems, strabismus, etc.)
☐ Dental? (Cavities, late tooth eruption, etc.) ☐ Neurologic Problems? (Seizures, tremors, brain malformations, abnormal muscle tone, etc.)
☐ Headaches? (Migraines, etc.) ☐ Lung problems? (Asthma, lung disease, breathing problems)
☐ Cardiovascular/Heart problems? (heart defects, murmurs, irregular rhythm, valve problem, circulation)
☐ High or low blood pressure?
☐ Stomach/Intestinal/Esophageal problems? (reflux/heartburn, ulcers, constipation, abdominal pain)
☐ Liver problems?
☐ Genitalia/Urologic Problems? (undescended/small testicles, problems with urination, hernia, infections)
☐ Abnormal Pubertal development? (early, delayed or abnormal puberty, gynecomastia/breast enlargement
☐ Thyroid problems?
☐ Diabetes? ☐ Orthopedic/Rheumatologic problems (Malformation of limbs/hands/feet, joint problems/pain, flat feet, etc.)
☐ Back problems? (scoliosis, kyphosis, other back abnormalities)
Skin or Hair problems? (rashes, skin ulcers/sores, birthmarks, etc)
☐ Allergies? (food, environmental, medications)
☐ Blood problems (anemia, abnormal white blood cells, abnormal platelets)
☐ Frequent Infections? (skin, respiratory, urinary infections)
Has your child had any of the following diagnostic tests? (dates and results, if known)
□EEG (brain wave test)
□MRI □CT Scan
□Blood Test (other than routine blood count)
□Chromosomal/DNA testing
□Vision Test
□Other (specify)
Which other types of medical specialists have seen and evaluated/treated your child?
Has your child ever been hospitalized? ☐Yes ☐No Has your child ever had surgery? ☐Yes ☐No If hospitalized and/or surgery, when and why? ☐
Has your child ever had surgery? ☐ Yes ☐ No

Please list all current medications and supplements: Medication name: How Often? Dose Medication name: Dose How Often? Medication name: Dose How Often? **FAMILY MEDICAL HISTORY Mother**: Health, learning, mental health problems? □Yes □No If yes, please describe: Medications currently taking? Number of Brothers: Number of sisters: Numbers of Nieces/Nephews: Father: Health, learning, mental health problems? □Yes □No If yes, please describe: Medications currently taking? Number of Brothers: Number of sisters: Numbers of Nieces/Nephews: Are there any medical illnesses in other family members? (Please specify who) ☐Birth defect □Diabetes ☐Mental Retardation □Speech/Language delay ☐ High Blood Pressure □Learning Disability □Chromosomal disorder/genetic syndrome □Seizures □Depression □Autism/PDD □Kidney Disease □ Anxiety Problems □Alcohol/Drug Abuse Cancer □ADD/ADHD □Other: (Please describe)

Finding out about Sex Chromosome Aneuploidy – Prenatal Diagnosis

Tod	's date:					
Chil	s birth date:					
<u>Chil</u>	s current age:					
Whi	type of SCA does your child have? (47,XXX; 47,XXX; 47,XYY, etc):					
1.	low far along was your pregnancy when your child's diagnosis was made?					
2.	What type of prenatal testing identified your child's diagnosis (NIPT, blood test, CVS, amnio, etc)?					
3.	What was the reason you had prenatal testing performed (maternal age, abnormal ultrasound findings, no reason, doctor offered, etc)?					
4.	Vhat doctor ordered your prenatal testing (routine OBGYN, maternal fetal medicine doctor, IVF doctor, etc)?					
5.	Vere you told about the possibility of finding this diagnosis prior to testing?	_				
6.	Who provided you with information about the diagnosis? (routine OBGYN, maternal fetal medicine doctor, IVF doctor, genetic counselor, etc)?					
7.	olid you ever meet or speak with a genetic counselor or genetic doctor after getting the diagnosis?	_				
8.	low were you given information about the diagnosis? (in-person discussion, telephone conversation, written materials, etc)?					
9.	low much information was provided to you about the diagnosis when you were told?					
	1 2 3 4 5 6 7 8 9 10 'ery Little Adequate A lot					
	What information was provided?					
10.	n your opinion, was the provider who gave you information about the diagnosis well informed about the condition?					
11.	Vas this diagnosis tested for and confirmed after birth / postnatally in your baby? YES NO If yes, were results the same? YES 1	<u>10</u>				
12.	Other comments about your prenatal experience:	_				

X&Y CHROMOSOME VARIATION MEDICATION PROFILE – PART ONE - CURRENT MEDICATIONS

PLEASE LIST THE MEDICATIONS YOUR CHILD IS CURRENTLY TAKING BELOW.

#1) Medication Name		
Dose and Frequency of Medication (e.g. one 250mg tablet two time	s per day (OR 250mg 3 times per day)
When was this medication started?	Which d	doctor started this medication?
Has the medication dosage been changed since the medication was If yes, how has it changed? Why was it changed?	s started?	Y □Yes □No
Why was the medication started? Which symptom(s) or problem(s)	is the med	dication intended to treat?
Has the medication helped these symptoms? ☐ Yes – the symptoms are significantly improved ☐ Yes – the symptoms are slightly improved Please explain your answer above:		 □ No – the symptoms are the same □ No – the symptoms are worse than before starting the medication
Does this medication have any side effects in your child? If yes, please explain.	□Yes	□No
#2) Medication Name_ Dose and Frequency of Medication (e.g. one 250mg tablet two time	s per day (OR 250mg 3 times per day)
When was this medication started? Has the medication dosage been changed since the medication was If yes, how has it changed? Why was it changed?		doctor started this medication? □ Yes □ No
Why was the medication started? Which symptom(s) or problem(s)	is the med	dication intended to treat?
Has the medication helped these symptoms? ☐ Yes – the symptoms are significantly improved ☐ Yes – the symptoms are slightly improved Please explain your answer above:		 □ No – the symptoms are the same □ No – the symptoms are worse than before starting the medication
Does this medication have any side effects in your child? If yes, please explain.	□Yes	□No
#3) Medication Name		
Dose and Frequency of Medication (e.g. one 250mg tablet two time	s per day (OR 250mg 3 times per day)
When was this medication started?		doctor started this medication? □Yes □No
Why was the medication started? Which symptom(s) or problem(s)	is the med	dication intended to treat?
Has the medication helped these symptoms? ☐ Yes – the symptoms are significantly improved ☐ Yes – the symptoms are slightly improved Please explain your answer above:		 □ No – the symptoms are the same □ No – the symptoms are worse than before starting the medication
Does this medication have any side effects in your child? If yes, please explain.	□Yes	□No

X&Y CHROMOSOME VARIATION MEDICATION PROFILE – PART TWO - PAST MEDICATIONS

PLEASE FILL OUT THE FOLLOWING ON ALL **PREVIOUS** MEDICATIONS. It is not necessary to fill this out for past antibiotics, etc.

#1) Medication Name	
Dose and Frequency of Medication (e.g. one 250mg tablet two times per day OR 250mg 3 times	per day)
When was this medication started? Which doctor start	ted this medication?
When was this medication stopped?	
Was the medication dosage been changed during the time the medication was taken? □Yes	□No
If yes, how was it changed? Why was it changed?	
Why was this medication started? Which symptom(s) or problem(s) was the medication intended	to treat?
Did the medication help these symptoms?	
☐ Yes – the symptoms significantly improved	
☐ Yes – the symptoms slightly improved	
☐ No – the symptoms were the same	
□ No – the symptoms were worse than before starting the medication	
Please explain your answer above:	
Why was this medication stopped?	
Did this medication have any side effects in your child? ☐Yes ☐No	
If yes, please explain.	
#2) Medication Name	
Dose and Frequency of Medication (e.g. one 250mg tablet two times per day OR 250mg 3 times	per day)
When was this medication started? Which doctor start	ted this medication?
When was this medication stopped?	
Was the medication dosage been changed during the time the medication was taken? □Yes	□No
If yes, how was it changed? Why was it changed?	
Why was this medication started? Which symptom(s) or problem(s) was the medication intended	to treat?
Did the medication help these symptoms?	
☐ Yes – the symptoms significantly improved	
☐ Yes – the symptoms slightly improved	
☐ No – the symptoms were the same	
☐ No – the symptoms were worse than before starting the medication	
Please explain your answer above:	
Why was this medication stopped?	
Did this medication have any side effects in your child? ☐Yes ☐No	
If yes, please explain.	