



MR0080

WN SYNDROME PROGRAM
AKE FORM
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OB:

Patient Information:

First Name _____ Last Name _____

Street Address _____ Apt _____

City _____ State _____ Zip Code _____ Gender _____

Home Phone _____ Date of Birth _____

Mother Name _____ Mother's occupation/place of work: _____

Mother Cell _____ Mother Email _____

Father Name _____ Father's occupation/place of work: _____

Father Cell _____ Father Email _____

If applicable:

Legal Guardian _____ Son or Daughter lives with _____

Step-parents _____ Primary Language(s) spoken at home _____

Interpreter needed for this visit? Yes No If yes, what language? _____

Pediatrician Information:

Pediatrician Name _____

Practice Name _____

Street Address _____ Suite _____

City _____ State _____ Zip Code _____

Office Phone _____ Office Fax _____

What are your major medical/developmental concerns for your child at this time? This information will help us tailor the visit to best suit your needs.

1) _____

2) _____

3) _____

Name:

Name:

CH MRN#:

What are three major strengths that you feel your child has at this time?

- 1) _____
- _____
- 2) _____
- _____
- 3) _____
- _____

Diagnosis:

Which diagnosis did you receive? PRENATAL POSTNATAL

If prenatal, which diagnostic test? amniocentesis CVS

Has your child had blood chromosome studies done? YES NO

Have you been given the chromosome results? YES NO

If yes, who discussed these results with you? _____

What was your child's diagnosis? Trisomy 21 Mosaic Translocation Not Sure

Pregnancy Information:

Please describe any complications you had with your pregnancy: _____

Birth History: (please complete as much as you can remember)

Name of Birth Hospital _____

Length of Infant's Hospitalization _____ Delivered at _____ weeks gestation.

Type of Delivery? Vaginal Planned C-Section Emergency C-Section

Birth Weight _____ Birth Length _____ Head Circumference _____

Apgar Scores _____ Mother's Age at Delivery _____

How many times has mother been pregnant? _____ How many children does mother have? _____

Please describe any complications your child had in the newborn period _____

Name:

Name:

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Additional Medical History: (briefly describe all that apply to your son or daughter)

Hospitalizations: number of inpatient hospitalizations () _____

Surgeries: _____

Serious Illnesses: _____

Accidents/Injuries: _____

Allergies to Medications: _____

Other Allergies: _____

Allergy Testing: Yes No When: _____ Results: _____

SPECIALISTS: Please list all the specialists who are **CURRENTLY** involved in your child's care:

Specialty	Provider Name	Location of Practice	Last Visit Date?	Comments
<i>e.g., cardiologist</i>	<i>Dr. Smith</i>	<i>Children's</i>	<i>May 12, 2008</i>	<i>F/up one year</i>
Cardiologist				
Endocrinologist				
Gastroenterologist				
Otolaryngologist				
Ophthalmologist				
Orthopedist				
Dentist				

Name:

Name:

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Specialty	Provider Name	Location of Practice	Last Visit Date?	Comments
other:				
other:				

In the past **12 months**, has your child seen an **audiologist** for a formal hearing examination?

YES NO if yes, at Children's? YES NO upcoming appt: _____

In the past **12 months**, has your child seen an **ophthalmologist** for a formal eye examination?

YES NO if yes, at Children's? YES NO upcoming appt: _____

Has your child **ever** had a **sleep study** performed for obstructive sleep apnea?

YES NO if yes, at Children's? YES NO when and where: _____

In the past **6 months**, has your child seen a **dentist**?

YES NO if yes, at Children's? YES NO upcoming appt: _____

In the past **12 months**, has your child had **thyroid blood work** done?

YES NO if yes, at Children's? YES NO if no, please send results prior to appointment

Has your child **ever** had blood work done for **celiac disease**?

YES NO if yes, at Children's? YES NO if no, please send results prior to appointment

Has your child **ever** had a **neck xray** ("c-spine") done?

YES NO if yes, at Children's? YES NO if no, please send results prior to appointment

In the past **12 months**, has your child been tested for **iron-deficiency** with a hemoglobin blood test?

YES NO if yes, at Children's? YES NO if no, please send results prior to appointment

Name:

Name:

CH MRN#:

Immunizations:

Are your child's immunizations up to date? YES NO

Did your child receive the flu shot this past year? YES NO

Current Medications:

Please list all CURRENT medications, over-the-counter medicines, supplements, or natural products.

Name	Amount (in milligrams)	How often?	Date first begun
<i>(e.g., levothyroxine)</i>	<i>25 micrograms</i>	<i>daily</i>	<i>2/1/10</i>

Assistive Devices:

Does your child use any assistive devices or special equipment on a daily basis? (e.g. glasses, hearing aids, augmentative communication devices, etc) YES NO

If yes, please provide details _____

Sibling Information:

Sibling's Name _____ DOB _____

Medical/Behavior/Educational Problems _____

Sibling's Name _____ DOB _____

Medical/Behavior/Educational Problems _____

Sibling's Name _____ DOB _____

Medical/Behavior/Educational Problems _____

Sibling's Name _____ DOB _____

Medical/Behavior/Educational Problems _____

Name:

Name:

CH MRN#:

Conditions in the Biological Parents: Please check the box for everyone in the family of the person with DS who has had any of the following health problems:

Condition	Mother	Father	Sibling	Other (if so, who?)
Down syndrome	_____	_____	_____	_____
Diabetes	_____	_____	_____	_____
High Blood Pressure	_____	_____	_____	_____
High Cholesterol	_____	_____	_____	_____
Thyroid Disease	_____	_____	_____	_____
Arthritis	_____	_____	_____	_____
Dementia/Alzheimer's Disease	_____	_____	_____	_____
Heart Disease	_____	_____	_____	_____
Seizures	_____	_____	_____	_____
Stroke	_____	_____	_____	_____
Cancer (_____)	_____	_____	_____	_____
Mental Health (_____)	_____	_____	_____	_____

Additional medical history for mother

Additional medical history for father



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DB:

Review of Systems: Please circle the issues that your child has had in the past 12 months and right now.

Concern	Past 12 months?		Right now?		more details
	Yes	No	Yes	No	
GENERAL:					
fever	Yes	No	Yes	No	
weight changes	Yes	No	Yes	No	
increasing fatigue	Yes	No	Yes	No	
new behavioral problem	Yes	No	Yes	No	
GASTRO-INTESTINAL:					
stomach complaints	Yes	No	Yes	No	
vomiting	Yes	No	Yes	No	
nausea	Yes	No	Yes	No	
reflux	Yes	No	Yes	No	
constipation	Yes	No	Yes	No	
diarrhea	Yes	No	Yes	No	
underweight	Yes	No	Yes	No	
overweight	Yes	No	Yes	No	

Name:

Name:

CH MRN#:

Concern	Past 12 months?		Right now?		more details
EYES:					
concerns about vision	Yes	No	Yes	No	
lazy eye	Yes	No	Yes	No	
cataracts	Yes	No	Yes	No	
wears glasses or contacts	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
GENITO-URINARY					
urinary tract infections	Yes	No	Yes	No	
kidney problems	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
CARDIAC:					
murmur	Yes	No	Yes	No	
chest pain	Yes	No	Yes	No	
poor exercise tolerance	Yes	No	Yes	No	
sweating when feeding	Yes	No	Yes	No	
high blood pressure	Yes	No	Yes	No	
Other:	Yes	No	Yes	No	

Name:

Name:

CH MRN#:

Concern	Past 12 months?		Right now?		more details
RESPIRATORY:					
pneumonia	Yes	No	Yes	No	
wheezing/asthma	Yes	No	Yes	No	
difficulty breathing	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
SKIN:					
rash	Yes	No	Yes	No	
dry skin	Yes	No	Yes	No	
excema	Yes	No	Yes	No	
Alopecia/hair loss	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
EAR, NOSE, THROAT:					
ear infections	Yes	No	Yes	No	
wax build up	Yes	No	Yes	No	
hearing loss	Yes	No	Yes	No	
tympanostomy tubes	Yes	No	Yes	No	
hearing aids	Yes	No	Yes	No	

Concern	Past 12 months?		Right now?		more details
	Yes	No	Yes	No	
sinus problems	Yes	No	Yes	No	
frequent runny nose	Yes	No	Yes	No	
frequent sore throat	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
ALLERGY/IMMUNOLOGY:					
seasonal allergies	Yes	No	Yes	No	
allergy to food	Yes	No	Yes	No	
new autoimmune diagnosis (<i>e.g., Hashimoto's thyroiditis; alopecia</i>)	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
NEUROLOGIC:					
seizures	Yes	No	Yes	No	
abnormal movements	Yes	No	Yes	No	
weakness	Yes	No	Yes	No	
not able to do things as they used to	Yes	No	Yes	No	
new change in bladder function	Yes	No	Yes	No	
new change in bowel function	Yes	No	Yes	No	

Concern	Past 12 months?		Right now?		more details
HEMATOLOGIC:					
anemia	Yes	No	Yes	No	
TMD (transient myeloproliferative disorder)	Yes	No	Yes	No	
leukemia	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
MUSCULOSKELETAL:					
neck pain	Yes	No	Yes	No	
abnormal position of head	Yes	No	Yes	No	
atlantoaxial instability	Yes	No	Yes	No	
wears braces	Yes	No	Yes	No	
scoliosis	Yes	No	Yes	No	
joint problems	Yes	No	Yes	No	
difficulty walking	Yes	No	Yes	No	
fall frequently	Yes	No	Yes	No	
head tilt	Yes	No	Yes	No	
morning stiffness	Yes	No	Yes	No	
change in use of arms or legs	Yes	No	Yes	No	

Concern	Past 12 months?		Right now?		more details
	Yes	No	Yes	No	
new-onset weakness	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
ENDOCRINE:					
excessive thirst	Yes	No	Yes	No	
too hot/too cold	Yes	No	Yes	No	
tired, sluggish	Yes	No	Yes	No	
diabetes	Yes	No	Yes	No	
urinates more frequently	Yes	No	Yes	No	
hyperthyroidism	Yes	No	Yes	No	
hypothyroidism	Yes	No	Yes	No	
other:	Yes	No	Yes	No	
FEEDING/SWALLOWING:					
trouble eating food or drinking liquids	Yes	No	Yes	No	
aspiration	Yes	No	Yes	No	
choking/gagging with food or drinks	Yes	No	Yes	No	
special dietary needs	Yes	No	Yes	No	

Concern	Past 12 months?		Right now?		more details
DENTAL/MOUTH:					
gum disease	Yes	No	Yes	No	
gum problems	Yes	No	Yes	No	
cavities	Yes	No	Yes	No	
difficulty brushing his/her teeth daily	Yes	No	Yes	No	
floss regularly	Yes	No	Yes	No	
braces/retainer	Yes	No	Yes	No	
TOILETING:					
toilet trained	Yes	No	Yes	No	
accidents with urine or stool	Yes	No	Yes	No	
difficulty with constipation	Yes	No	Yes	No	
other:	Yes	No	Yes	No	

For Females –

Has her period begun? YES NO if yes, age it began _____

How often does she get it? _____ How long does it last? _____

Has she ever had a pap smear? YES NO if yes, date of last exam _____

Has her PAP ever been abnormal? YES NO Is birth control needed? YES NO

For Males -

Does he have a hernia? YES NO Does he have an undescended testicle? YES NO



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SLEEP:

Does your son or daughter snore?	yes	no
Does your son or daughter exhibit gasps, snorts, choking during sleep?	yes	no
Does your son or daughter breathe through an open mouth during sleep?	yes	no
Does your son or daughter have night terrors, sleep walk or sleep talk?	yes	no
Does your son or daughter wet the bed?	yes	no
Does your son or daughter sleep on multiple pillows?	yes	no
Does your son or daughter sleep in strange positions (seated upright, folded over, or with the neck hyperextended)?	yes	no
Does your son or daughter have morning headaches?	yes	no
Has your son or daughter gained a lot of weight recently?	yes	no
Have there been changes in school performance or behavior concurrent to weight gain and/or onset of sleep disturbances?	yes	no
Does your son or daughter not seem refreshed despite getting an adequate amount of sleep?	yes	no
Does your son or daughter fall asleep in the car on short drives, at school, or nap in an age inappropriate way?	yes	no
Is there a family history of obstructive sleep apnea?	yes	no

Name:
CH MRN#:

EMOTIONS AND BEHAVIORS:

Overall, do you feel that your son or daughter has any problems with feelings or behaviors; in addition, to any questions you may have about their development or physical health? Please check:

= no problems = minor problems = major problems

What are your major emotional/behavioral concerns for your child at this time?

Many of the following items may not apply to your son or daughter. We would appreciate it if you can respond to all the items to the best of your knowledge.

For each item listed below, now or in the past six months please check:

Concern	Not True	Sometimes True	Very True
Appears sad, downcast, unhappy			
Is tense, anxious, worried			
Is distressed about being alone			
There is a change in his/her usual emotions/behaviors			
There is a change in his/her interest in life /activities			



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DB:

Concern	Not True	Sometimes True	Very True
Is forgetful, has trouble remembering things			
Refuses to go to a program, activity or school			
Is excessively distressed if separated from familiar person			
Fears particular things or situations, e.g. dark or animals			
Has temper tantrums			
Cries easily or for no reason over small upsets			
Throws or breaks objects			
Hits self or bites self			
Bangs head			
Is irritable			
Kicks, hits others			
Has mood changes rapidly for no apparent reason			
Is unrealistically happy or elated			
Is impulsive, acts without thinking			
Is overactive, restless, unable to sit still			

Name:

CH MRN#:

Concern	Not True	Sometimes True	Very True
Is easily distracted from his/her task, e.g. by noises			
is uncooperative, disobeys			
Moves slowly, is under active			
Has poor sense of danger			
Deliberately runs away			
Is aloof, in his/her own world			
Prefers to do things on his/her own			
Doesn't respond to others' feelings			
Arranges objects or has routine in strict order			
Gets upset over small changes in routine or environment			
Flicks, taps, twirls objects repeatedly			
Gets obsessed with an idea or activity			
Talks to self or imaginary people or objects			
Avoids eye contact, won't look you in the eye			
Smells, tastes or licks objects			
Chews or mouths objects or body parts			
Eats non-food items			

Name:
CH MRN#:

Concern	Not True	Sometimes True	Very True
Grinds teeth			

Safety Concerns:

Do you have any safety concerns for your son or daughter? YES NO

Extra Supports:

Name of Organization	We are connected	I would like more information
Massachusetts Down Syndrome Congress	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
Federation for Children with Special Needs	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
The Arc of Massachusetts	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
Supplemental Security Income (SSI)	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
Masshealth/Commonhealth	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
Dept. of Developmental Disabilities (formerly known as DMR)	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
National Down syndrome Organizations	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
Special Olympics of Massachusetts	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO

Name of Organization	We are connected	I would like more information
Local Parent Support Groups if connected, please list: _____ _____	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO
Other supports, please name:	<input type="checkbox"/> YES <input type="checkbox"/> NO	<input type="checkbox"/> YES <input type="checkbox"/> NO

Do you have an estate plan for your child? YES NO

Do you have any social or financial needs regarding support for your child or family? YES NO

Education:

Is your child in school? YES NO

Name of School _____ Grade _____

Placement Type is: (please check)

inclusion partial inclusion substantially separate home school

other _____

Do you feel the Individualized Education Plan is currently meeting your son's or daughter's needs? YES NO

Name:
CH MRN#:

Does your son or daughter receive any special supports or services? YES NO

Does your son or daughter attend an after-school program? YES NO

Does your son or daughter receive any educational supports, therapy, or programs outside of the school setting? YES NO _____

Does your son or daughter participate in any school related groups, teams, or activities?

YES NO _____

Recreation:

Does your child participate in a form of exercise on a regular basis? YES NO

Does your child participate in any social or recreation programs outside of school? YES NO

Please list activities: _____

Parent (if patient under 18 years of age)
Guardian (relationship to patient)

Please Print & Sign

Date