



We are a "little" group of families reaching out for one another's support on dealing with this medical rarity and how it affects all of our lives.

SURVEY

We appreciate your time in completing this survey. This survey is quite detailed. We need this information for our database to obtain information to help further educate doctors/teachers/specialists in helping our children/family members.

This will also help us answer questions that others may have when they have a newborn diagnosed with Robinow Syndrome.

This data will be kept completely confidential, only specifics will be used to help aide in finding answers to this rare anomaly, no names or personal information will be given out to anyone without prior written consent.

Thank You!

PARENT/FAMILY INFORMATION

(PLEASE COMPLETE ONE SURVEY FOR EACH AFFECTED PERSON - PRINT CLEARLY)

First name: _____

Last name: _____

Marital status: Married Single Separated
 Divorced Domestic Partners
 Widow/Widower Remarried
 Engaged

Spouses name: _____

Street address: _____

City: _____ State: _____ Zip: _____

County: _____ Country: _____

Home phone: _____ - _____ - _____

Best time to call: _____

Work phone: _____ - _____ - _____

Best time to call: _____
(only if you can be called there)

Your occupation: _____

Other parent's occupation: _____

Number of children: _____

Total pregnancies: _____ Living _____ Died _____
_____ Miscarriage
_____ Stillborn
_____ Multiples

Ethnic Background: Caucasian
 Asian-American
 Native-American
 African-American
 Hispanic
 Other: _____

Languages spoken fluently: _____ by _____
(other than English)
 Mother Father
 Child

Could you be a hospital volunteer and help a parent whose child needs to be or is hospitalized by visiting them at the hospital?
 Yes No

Which Hospitals?: _____

How did you hear about the **Robinow Syndrome Foundation**?

CHILD INFORMATION

First name: _____

Last name: _____

Birthdate: _____ / _____ / _____: Male Female
 Birth Foster Adopted Multiple birth

Robinow Syndrome Diagnosis: Dominant Recessive
 Confirmed Waiting
 Not diagnosed as either

Other diagnoses/secondary disabilities/or conditions: _____

When was Robinow Syndrome diagnosed:

Before birth At birth At age: _____

Apgar: _____ / _____ Birth weight: _____
(Score at birth) *(40 weeks is normal)*

Length of pregnancy: _____

Has your child ever had a bad reaction to a vaccine: Yes No
 High fever High pitched scream
 Seizure Other: _____

Date of 1st known seizure: _____

Type of seizure: _____

Medication(s): _____

Explain vaccine reaction: _____

I recommend the following to other parents:

Pediatric Neurologist: _____
Cardiologist: _____
Heart Surgeon: _____
Orthopedic Surgeon: _____
Pediatric Urologist: _____
Endocrinologist: _____
Geneticist: _____
Craniofacial Surgeon: _____
Psychiatrist: _____
Psychologist: _____
Pulmonary Specialist: _____
Other: _____
Hospitals/Clinics: _____

Please check the appropriate boxes and sign and date:

- Yes No Please put me on the newsletter mailing list
- Yes No If possible, I would like to be sent the name, addresses and phone no. of other parents
- Yes No You may let another person call me to talk
- Yes No You may release my name to people interested in contacting families about research involving my child's condition
- Yes No Please do NOT release any of the above information to another family!

Circle all that apply:

You may release my (Name Address Phone) to other parents, doctors or specialists.

(SIGNATURE - REQUIRED) DATE

Please check all items that best describe your child.

COGNITIVE FUNCTIONING LEVEL

- At developmental age level
- Developmentally delayed
 - Mild Moderate Severe
- Functions at age level: _____
- Gifted IQ Score: _____

MOBILITY

- Normal for age
- Walks independently
- Walks with crutches
- Walker
- Crawls
- Scoots
- Rolls
- Wheelchair
- Powerchair
- Manual
- No mobility
- Kicks
- Grabs toys

TOILET SKILLS

- Normal for age
- In diapers
- Diapers only at night
- In training
- Will always need diapers
- Potty trained at age: _____

VISION

- Normal for age
- Impaired
- Blind
- Glasses
- Contact lenses
- Photophobia (*light sensitivity*)
- Other, explain: _____

SPEECH

- Normal for age
- Nonverbal communication
- Does not communicate
- Coos
- Eye contact
- Communicates only with a few words
- Difficult to understand
- Speaking device
- Sign language
- Smiles
- Laughs

DIET / EATING SKILLS

- Normal for age
- Special diet
- Some help needed
- Feeding tube
 - Button
 - NG
 - Line
- Regular diet
- No help needed
- Fed by others
- Breast-fed
 - now was
 - months: _____

Write in any feeding difficulties in detail with the age of child at time of difficulty: _____

HEARING

- Normal for age
- Deaf
- Uses sign language
- Range of Hearing: _____ Right; _____ Left
- Range with aids: _____ Right; _____ Left
- Frequent ear infections
- Starting: _____ Age: _____
- Impaired
- Reads lips
- Wears hearing aids
- Tubes in ears
- # of times: _____

BEHAVIOR

- Normal for age
- Overly affectionate
- Self abusive
- Aggressive
- Hyperactive
- Passive
- Impulsive
- Defiant

SELF-HELP

- Normal for age
- Dresses with some help
- Puts on shoes & ties
- Undresses self
- Dresses self no help
- Does not dress self
- Puts on shoes/help tying
- Undresses with help

SPECIAL CONDITIONS / EQUIPMENT

Circle if the equipment is being used now
Underline if the equipment was used in the past

- Apnea monitor
- Communication device
- IV
- Shunt
- Tracheotomy
- Computer
- Heart monitor
- Oxygen
- Suction
- Ventilator

Other (list): _____

HOSPITALIZATIONS / SURGERIES

List hospital, reason for surgery and indicate if it was a **GOOD** or **BAD** experience and why: _____

GENERAL INFORMATION

- I have enclosed a photo(s):
 - For **Robinow Syndrome Foundation** family album
 - For **Robinow Syndrome Foundation** website (*Robinow.org*)
 - For **Robinow Syndrome Foundation** newsletter:

“SMALLTALK”

(Please indicate if you want your name or address published.)

 (SIGNATURE - REQUIRED) DATE

- I have enclosed a donation of \$ _____ to help with the **Robinow Syndrome Foundation** expenses.
- I regret I can not donate at this time.

Tell us how **Robinow Syndrome** affects your child. Add anything not covered above. Check all that apply.

Birth weight: _____

Family history of Robinow Syndrome: _____

Normal pregnancy: _____

Head size at birth: _____

Presently: _____ At the age of: _____

Birth weight: _____

FACIAL FEATURES:

- Wide set eyes
- Short upturned nose
- Large eye openings
- Long or short Philtrum
- Facial nevus (*birthmark*)
- Low nasal bridge
- Prominent forehead
- Triangular mouth
- Recessed or small chin
- Low set ears

TEETH/ORAL FEATURES:

- Missing uvula
- Missing baby teeth
- Dentures
- Braces
- Cleft palate
- Cleft lip
- Cleft (*indent*) on tip of tongue
- Small cleft (*indent*) in middle of bottom lip
- Large tonsils/adenoids
- Missing adult teeth
- Crowded
- Submucous
- Gum hypoplasia (*thick*)
- High palate

What age did teeth first appear: _____

List any other dental issues: _____

MUSCULOSKELETAL:

List percentile on/off growth chart for age: _____

- Short stature
- Segmentation defects
- Scoliosis
- Delayed bone age
- Butterfly vertebra
- Spina Bifida occulta
- Inguinal or umbilical hernias
- Pectus excavatum (*sternum is abnormally depressed*)
- Vertebral abnormalities
- Fused vertebra
- Rib defects
- Hemivertebra
- Tethered spinal cord
- Fused vertebra

EXTREMITIES:

Arms

- Lack of supination/pronation of forearms
(rotation palm down, palm up)
- Dislocated elbow right left both

Hands

- One crease in palm of hand
(transvers palmar crease)
 - Small hands
 - Small fingers
 - Webbed fingers: *(which ones):* _____
 - One joint crease on each finger *(palm up)* instead of two
 - Hypoplastic fingernails *(underdeveloped)*
 - Curvature of fingers
(which ones, which hand): _____
 - Hyperextension of fingers
 - Contracture of any fingers *(will not fully straighten)*
(which ones, which hand): _____
- Are fingers shortened: mildly moderately

Legs

- Hip dislocation
- Underdeveloped pelvis
- Difficulty walking
- Small toes
- High arch /wide feet
- Underdeveloped hips
- Leg / knee pains
- Small feet
- Webbed toes

Explain: _____

Trunk

- Umbilical hernia(s) *(details):*

Genitourinary:

- Kidney reflux _____
- Small bladder

Please describe any medical issues with the following:

- Kidneys: _____
- Ureters: _____
- Bladder: _____
- Urethra: _____
- Hypospadias *(type if known):* _____

- Testicles: Descended Undescended
 One or both Normal size
 Underdeveloped

- Phallus: Normal Shortened
 Buried

- Labia: Normal Underdeveloped

- Clitoris: Normal Underdeveloped/small

Females: list any menstrual or child birthing issues:

Hormones: *(Endocrinology):*

Please describe in detail any hormonal issues and treatments: _____

Others:

- Gastroesophageal reflux

