

# C

## ONTACTS

*WE ALL WANT TO TALK TO JUST ONE OTHER PERSON WHO UNDERSTANDS.  
SOMEONE WHO HAS HAD THE SAME EXPERIENCE.  
As we continue to grow and more people become aware of our group, the needs of those  
contacting us for information continues to expand.*

*As part of our contact program we have those that are:*

*Directly Affected an adult with Noonan syndrome.*

*Indirectly Affected a parent or guardian of a child with Noonan syndrome.*

*G.R.A.N.S. (Grandparents Relative Advocating for Noonan Syndrome) those that are not  
the parent or guardian but are affected because they are the Grandparents, Relatives or  
friends of a person with Noonan Syndrome.*

*N.A.P. We have added a new classification to our contact sheet, N.A.P. (Noonan Angel  
Parents/ People). These people have had someone they love die from complications associ-  
ated with Noonan syndrome.*

*Professionals doctors, teachers etc. taking an interest in those affected by Noonan syn-  
drome*

*As we come to a close of 1998 please take a moment to fill out the  
new contact form, and forward it to:*

*TNSSG, Inc.  
P O Box 145  
Upperco, MD 21155*

**WILL YOU BE A FRIEND YOU CAN CALL?**

♥ TNSSG, Inc. Contact Release Form  
NAME OF CONTACT

♥ LAST NAME: \_\_\_\_\_

♥ FIRST NAME: \_\_\_\_\_

♥ NAME OF PERSON AFFECTED WITH NS: \_\_\_\_\_

DATE OF BIRTH:

♥ \_\_\_\_\_

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

*Inherited:*

*Sporadic Occurrence/ Mutation*

**HOW ARE YOU AFFECTED?** (please indicate)

♥ **Directly Affected** (an adult with Noonan syndrome.) \_\_\_\_\_

♥ **Indirectly Affected** (a parent or guardian of a child with Noonan syndrome.) \_\_\_\_\_

♥ **G.R.A.N.S.** (Grandparents Relative Advocating for Noonan Syndrome.) \_\_\_\_\_

♥ **N.A.P.** (Noonan Angel Parents/ People). ( These people have had someone they love die from complications associated with Noonan syndrome.) \_\_\_\_\_

♥ **Professionals** (doctors, teachers etc. taking an interest in those affected by Noonan syndrome)

♥ SIBLINGS: \_\_\_\_\_ birth date \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

♥ \_\_\_\_\_ birth date \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

♥ \_\_\_\_\_ birth date \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

♥ MAILING ADDRESS: \_\_\_\_\_

♥ CITY: \_\_\_\_\_ STATE: \_\_\_\_\_

♥ ZIP: \_\_\_\_\_ COUNTRY: \_\_\_\_\_

♥ PHONE NUMBER: \_\_\_\_\_ - \_\_\_\_\_

♥ E-MAIL ADDRESS: \_\_\_\_\_

♥ NEW CONTACT: \_\_\_\_\_ CHANGE: \_\_\_\_\_

♥ SIGNATURE: \_\_\_\_\_ DATE \_\_\_\_\_

**PLEASE CHOOSE ONE**

♥ ADD MY NAME TO THE CONTACT LIST AND WEB SITE CONTACT PAGE : \_\_\_\_\_

♥ ADD MY NAME TO THE CONTACT LIST ONLY (published quarterly in *The Noonan Connection*): \_\_\_\_\_

♥ I HEREBY AUTHORIZE RELEASE OF MY NAME, MY CHILD'S NAME AND THE INFORMATION ON THESE FORMS TO THE NOONAN SYNDROME SUPPORT GROUP AND THE FAMILIES INVOLVED THEREIN.

♥ ANYONE WANTING TO BE ON THE CONTACT LIST OR WEB SITE MUST SIGN AND RETURN THE RELEASE FORM.

NAME \_\_\_\_\_

AGE \_\_\_\_\_

D-O-B M \_\_\_ D \_\_\_ Y \_\_\_

**♥LIST OF NS CHARACTERISTICS/SYMPTOMS♥**

**♥MUSCULAR/**

**SKELETAL DEFECTS**

- \_\_\_ Cervical spine fusion(neck)
- \_\_\_ Scoliosos
- \_\_\_ Prominence of breast bone
- \_\_\_ Depression of breast bone
- \_\_\_ Cubitus Valgus(elbow deformity)
- \_\_\_ Polydactyly(having extra fingers or toes)
- \_\_\_ Joint contractures or tightness
- \_\_\_ Joint hyperextensibility or looseness
- \_\_\_ Osteoporosis
- \_\_\_ Retarded Bone age
- \_\_\_ Shortness of stature
- \_\_\_ Broad Forehead
- \_\_\_ Small chin
- \_\_\_ Cherubism cheekbone deformity causing a lowering of the eyelid (appears as though person is looking upward as in angels and cherubs in renaissance paintings)
- \_\_\_ Inguinal and umbilical hernias
- \_\_\_ Winging of the scapula
- \_\_\_ Hypotonia(low muscle tone)
- \_\_\_ Other, please explain

**♥GENITO-URINARY SYSTEMS**

- \_\_\_ Underdeveloped primary sex organs
- \_\_\_ Cryptocordism(undescended testicles)
- \_\_\_ Hypospadias(urethral opening misplaced)
- \_\_\_ Other Please explain

**♥LYMPHATIC SYSTEM**

- \_\_\_ Posterior Cervical Hygroma(webbed neck)
- \_\_\_ Lymphedema(build-up of body fluid due to

- poor functioning of the lymphatic system
- \_\_\_ Other Please explain

**♥BEHAVIORAL/SOCIAL**

- \_\_\_ Chronic crying in infancy
- \_\_\_ Overly Sensitive
- \_\_\_ Stubborn
- \_\_\_ Irritable
- \_\_\_ Obsessive behavior; liking of routine
- \_\_\_ Overactive
- \_\_\_ Underactive
- \_\_\_ Squirmy/Fidgety
- \_\_\_ Withdrawn/Depressed
- \_\_\_ Extreme mood swings
- \_\_\_ Aggressive behavior
- \_\_\_ Short attention span
- \_\_\_ Other please explain

**♥DEVELOPMENTAL**

- \_\_\_ Delayed puberty
- \_\_\_ Lack of sexual development
- \_\_\_ Clumsy; poor coordination
- \_\_\_ Gross motor delays
- \_\_\_ Fine motor delays
- \_\_\_ Possible mental retardation
- \_\_\_ Mental retardation
- \_\_\_ Learning disabilities
- \_\_\_ If diagnosed, please be more specific
- \_\_\_ Other please explain

**♥VISION/EYES**

- \_\_\_ Widely set eyes(hypertolerism)
- \_\_\_ Drooping of the eyelids(ptosis)
- \_\_\_ Refractive errors in vision
- \_\_\_ Inward or outward turning of the eyes
- \_\_\_ Strabismus(crossed eyes)
- \_\_\_ Anterior Uvetis(inflammation of the front part of the eyes(iris, cornea etc.)

- \_\_\_ Nystagmusjerking movement of the eyes
- \_\_\_ Other; please explain

**♥SKIN**

- \_\_\_ Edema of the back of hands and tops of feet
- \_\_\_ Simian creases; deeply grooved palms and bottoms of feet
- \_\_\_ Hirsutism(excessive hair growth on body parts)
- \_\_\_ Curly Hair
- \_\_\_ Low posterior hairline
- \_\_\_ Cutaneous Lymphangioma(wart-like growth on the skin, very small, made up of abnormal lymph vessels)
- \_\_\_ Keloids(excessive buildup of scar tissue on the skin following a cut or surgery)
- \_\_\_ Over development of outer skin layer(hyperkeratosis)
- \_\_\_ Pigmented birthmarks(nevus)
- \_\_\_ Vitiglio(white patches on skin; lack of pigment cells)
- \_\_\_ Other; please explain

**♥CIRCULATORY**

- \_\_\_ Bruises easily
- \_\_\_ Vasculities(blood vessel inflammation;many types and causes)
- \_\_\_ Thrombocytopenia(low platelet count)
- \_\_\_ Amegakaryocytic Thrombocytopenia(low platelet count due to absence of platelet making cells; Blood Clotting Defects
- \_\_\_ Von Willebrand disease
- \_\_\_ Prolonged activated partial thromboplastin time

NAME \_\_\_\_\_

AGE \_\_\_\_\_

D-O-B M \_\_\_\_\_ D \_\_\_\_\_ Y \_\_\_\_\_

**♥CIRCULATORY**

**continued**

- Partial deficiency of Factor VIII:C
- Partial deficiency of Factor XI:C
- Partial deficiency of Factor XII:C
- Combined Coagulation deficiencies
- Other; please explain

**♥HEARING**

- Low set
- Incomplete folding of ears
- Thick helix of ear(outer rim)
- Chronic Otitis media(ear infections)
- Glue Ear(thick glue-like fluid behind ear drum can occur after recurrent ear infections)
- Hearing Loss(if yes, please explain type/range of loss)
- Other, please explain

**♥SPEECH AND LANGUAGE**

- Micrognathia(small mouth)
- High Arched palate
- Dental problems
- Hypernasality
- Articulation Difficulties
- Speech and Language delays
- Poor tongue control

\_\_\_\_ Other please explain

**♥NUTRITION AND EATING HABITS**

- Failure to thrive as infant
- NG Tube feedings
- Eating less than normal
- Faddy eater
- Digestive/Intestinal problems
- Frequent or forceful vomiting
- Swallowing difficulties
- G-Tube feedings
- Other, please explain

**♥PHYSICAL APPEARANCE**

- Large Head
- Small Head
- Triangular face shape
- Short neck, webbed neck, posterior cervical hygroma(extra skin on back of neck)
- Deeply grooved philtrum or top lip line
- Bluntly ended fingers
- Extra padding on fingers and toes
- Distended abdomen
- Other please explain

**♥HEART**

- Pulmonary Valvular Stenosis
- ASD/VSD
- Heart Murmur
- Cardiac Myopathy

\_\_\_\_ Other please explain

**♥MISCELLANEOUS**

- Elevated Alkaline Phosphate(an enzyme made the liver or bone indicating liver problem, vit K deficiency)
  - Convulsions
  - Seizures
  - Autoimmune Disfunction
  - Autoimmune Thyroiditis(disease of the thyroid gland immune system attacks thyroid gland)
  - Hypoparathyroidism(affects calcium balance in the body)
  - Malignant Hyperthermia(abnormal response to anesthesia causing extreme high temperature)
  - Hydrocephaly(fluid on the brain)
  - Other
- ♥PREGNANCY**
- Polyhydramnios
  - Fetal Ultrasound Discoveries such as cervical hygroma, etc. please explain
  - Other, please explain

List any surgeries:

Comments/history, special issues or concerns you would like to share:

If you would like to enclose a picture of your child that would be welcomed. If you would like this picture to appear in the Gallery of Stars on our web site please indicate this on the back of the picture and also sign the picture.