

4P- SUPPORT GROUP BIOGRAPHICAL INFORMATION

The 4p- Support Group has been collecting and organizing biographical data on individuals with 4p- (Wolf-Hirschhorn Syndrome being the main syndrome) for almost 20 years. This information is transferred to our Bio CD and is updated annually. Additionally, our organization is in beginning stages of building an International Registry. We encourage all parents who have children with 4p- to submit biographical information to us every 2 years.

Currently, the 4p- Support Group is participating in 2 projects to advance the medical community's knowledge of 4p- and Wolf-Hirschhorn Syndrome. By submitting your child's biographical information, you will be helping advance this knowledge. This is called a general data collection and your child will not be named in the research. However, once we receive your submitted form, we will mail you a consent form to be signed and returned to our Corporate Office. This simply allows us to share this information with our researchers - Dr. John C. Carey, Dr. Amy Calhoun, Dr. Sarah South, and their colleagues.

To submit and/or update your child's biographical file, complete the questions listed below. This information will be released only to members of the 4p- Support Group, and no other use is authorized without your expressed permission.

You have 2 options for submitting the Bio form.

1. **Preferred Method:** Save this file to your computer's hard drive. Answer questions specifically pertaining to your child. Once completed, email the file to president@4p-supportgroup.org. We also request that you submit up to 2 recent digital photos of your child – which will be included with the biography. You may mail the photos* to the address below, if you are unable to send it electronically. ** Option 1 allows for easy updates and submissions of your child's biography.
2. Print this form and legibly handwrite your responses to questions specifically pertaining to your child. Please keep your responses brief as they will be entered into an electronic database. We also request that you submit up to 2 recent digital photos of your child – which will be included with the biography. You may mail the photos* to the address below, if you are unable to send it electronically. Sign your completed survey and return it to our corporate office:

**4p- Support Group
c/o Amanda Lortz, President
131 Green Cook Road
Sunbury, OH 43074**

*Please note, photos will be kept on file and not returned.

PARENT'S INFORMATION

First & Last Name(s): _____ Address: _____

City/State (Prov)/ Zip (postal Code)/ Country (non-US): _____

Phone: (_____) _____ Email: _____ Website _____

Please list siblings and DOB(s): _____

Foster parent of this child? _____ Adopted? _____ Relative? _____ Parent's ages (at birth) Father _____ Mother _____

4P- CHILD

Name: _____ DOB: _____ Birth Weight: _____

Birth Length: _____ Gestation: _____ Born at (City): _____ at Hospital: _____

Current Age: _____ Current weight: _____ Current length (height): _____

DIAGNOSTIC INFORMATION

Doctor who ordered chromosome study or laboratory that performed study: _____

Date (or age) of diagnosis: _____ Report available: ___ Yes ___ No

Results

FISH: _____

High resolution: _____

Standard resolution: _____

Other DNA tests: _____

Sporadic/de novo: ___ Yes ___ No Translocation: ___ Yes ___ No ___ Unknown If yes, list chromosomes involved: _____

Ring Chromosome: ___ Yes ___ No ___ Unknown Inversion: ___ Yes ___ No ___ Unknown

Father's karyotype: _____ Mother's karyotype: _____

Result: _____ Result: _____

Doctor who ordered test: _____ Doctor who ordered test: _____

RELEASE

I, _____ Hereby give my permission (*please list any restrictions*) to release:

_____ This information and photo to members of the 4P- Support Group (*Professionals may also see these*).

_____ My address/Phone number to members of the 4P- Support Group

Date: _____ Signed: _____ Relation to 4P- Child _____

Restrictions, if any: _____

4P- Child's Initials _____

GESTATIONAL/BIRTH

Decreased fetal movements: ___Yes___No Comment:_____

Decreased amniotic fluid: ___Yes___No Comment:_____

Gestational age of birth:_____

CONGENITAL MALFORMATIONS

Heart Defect: ___Yes___No If yes, type:_____

Cardiac ultrasound performed: ___Yes___No

If yes, result:_____

Renal (kidney) defect: ___Yes___No Renal ultrasound performed: ___Yes___No

If yes, result:_____

Bladder Defect: ___Yes___No Type:_____

Vescicoureteral (genitourinary) reflux: ___Yes___No Type:_____

Genital Defect: ___Yes___No If male, hypospadias: ___Yes___No Cryptorchidism: ___Yes___No

Cleft lip: ___Yes___No Bilateral: ___Yes___No Unilateral: ___Yes___No

With cleft palate: ___Yes___No Cleft palate alone: ___Yes___No

Scalp defect: ___Yes___No Type:_____

Eye defect: ___Yes___No Type:_____

Glasses: ___Yes___No

Ear tags: ___Yes___No Ear pits: ___Yes___No

Any other malformations?

Comments on malformations:

HISTORY OF PNEUMONIAS

___Yes___No If yes, at what ages:_____ How many:_____

Describe:

RECURRENT OTITIS (Ear Infections)

___Yes___No If yes, at what ages:_____

How many:_____

Describe:

HEARING IMPAIRMENT

Hearing test done:___Yes___No Hearing impairment detected:___Yes___No

At what age:_____ If yes what type:___Conductive___Neural___Sensorineural

Degree of loss:___Mild___Moderate___Severe

Describe:

FEEDING DIFFICULTIES

Gastroesophageal reflux:___Yes___No Tube feeding:___Yes___No N/J tube:___Yes___No

Gastrostomy/tube placement:___Yes___No What age:_____

Continuous night time feeds:___Yes___No Bolus feeds:___Yes___No

Describe:

Oral feeds:___Yes___No Pureed foods:___Yes___No Solid foods:___Yes___No

Describe:

Swallow study performed:___Yes___No Aspiration:___Yes___No

Describe Results:

SKELETAL ANOMALIES

Scoliosis: ___ Yes ___ No

Other: ___ Yes ___ No

If yes, type:

Skeletal x-rays: ___ Yes ___ No

If yes, type:

ABNORMAL TEETH

Checked for it: ___ Yes ___ No

If yes, describe abnormalities:

SKIN CHANGES

___ Yes ___ No

Describe:

SEIZURES

Age of onset: _____ Triggered by a fever: ___ Yes ___ No Triggered by a vaccination: ___ Yes ___ No

Describe:

What types of seizures has your child had:

- ___ Tonic-Clonic ___ Tonic ___ Clonic ___ Myoclonic ___ Absence
- ___ Atonic ___ Complex Partial ___ Simple Partial ___ Atypical ___ Status Epilepticus

Medication used to stop Status Epilepticus: _____

Diagnosed Epileptic Syndrome: ___ Yes ___ No If yes, type: _____

EEG performed: ___Yes___No CT scan performed: ___Yes___No MRI performed: ___Yes___No

Describe:

Medications used or have been used and their effectiveness for your child's seizures:

Other non-medication treatments for seizures: ___Yes___No

Describe:

Other Comments:

SLEEP ABNORMALITIES

How long did/does your child sleep at night:

Does/did she/he wake up frequently during the night: ___Yes___No If yes, what time: _____

When awake at night, what does/did she/he do:

If sleep disturbances were present, at what age did they settle: _____

Medications used: _____

4P- Child's Initials _____

DEVELOPMENT

Please record the age at acquiring the following milestones, if applicable.

Smiles:_____ Sits up:_____ Stands:_____ Helps to dress:_____

Walks with support:_____ Walks w/o support:_____ Runs:_____ Feeds self:_____

Climbs stairs:_____ First words:_____ Joins 2 or 3 words to make a sentence:_____

Toilet control during the day:_____ Toilet control during the night:_____

What are the present cognitive abilities (IQ or functioning age level):_____

Psychological testing:___Yes___No

Describe:

Describe your child's current school program:

Is or has your child received the following therapies: ___PT___OT___Speech

Others, describe:_____

How is his/her comprehension:

PERSONALITY

SURGERIES

Please list all of the surgeries that your child has had, the reason for surgery, the type of procedure and the age at the time of the surgery.

OTHER COMMENTS

Growth Chart

*Complete as much information as you are able on the approximate growth points on the chart below.
You can obtain your child's growth measurements by contacting their primary physician's office.*

Age	Weight (in pounds & ounces)	Length (in inches)	Head Circumference (in centimeters)
At Birth			
1 Week			
1 Month			
2 Months			
3 Months			
4 Months			
5 Months			
6 Months			
7 Months			
8 Months			
9 Months			
10 Months			
11 Months			
1 Year			
2 Years			
3 Years			
4 Years			
5 Years			
6 Years			
7 Years			
8 Years			
9 Years			
10 Years			
11 Years			
12 Years			
13 Years			
14 Years			
15 Years			
16 Years			
17 Years			
18 Years			
19 Years			
20 Years			
30 Years			
40 Years			
50 Years			
60 Years			