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. All data is extremely useful, even if your child or adult with 4p- has passed away. International participation is greatly appreciated. The only requirement is that submissions must be sent to us in English.

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.

Follow the instructions below to submit and/or update your child's biographical file. This information will be released only to Full 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:** Go to http://4p-supportgroup.org/biographical-information/. Save the "Bio Form – Updated 2012" 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. Go to http://4p-supportgroup.org/biographical-information/. Print the "Bio Form – Updated 2012" file. You may also request them to be mailed to you by contacting Amanda Lortz at (740) 936-5095 or president@4p-supportgroup.org. 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 at the address below.

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

Submitting the Consent Form for the growth research:

The consent forms for our growth research project are available at http://4p-supportgroup.org/biographical-information/ or you may request them to be mailed to you by contacting Amanda Lortz at (740) 936-5095 or president@4p-supportgroup.org. Sign and submit your consent form via email to president@4p-supportgroup.org or mail to the address below. You may also fax to (801) 581-8943 Attn: Dr. Amy Calhoun. This is a secure fax. Once we have received your consent, we will sign and return a copy to you for your records.

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

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

Gastroesphageal 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:_____

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 Data

Please complete as much of the chart as you are able. You can obtain your child's measurements by contacting his or her primary physician. You may also, if you prefer, directly attach a copy of your child's formal growth chart from his or her primary physician.

Age	*Date of measurement (if known)*	*Weight (pounds and ounces)*	*Length (inches)*	*Head Circumference (centimeters)*
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				
6years				
7 years				
8 years				
9years				
10years				
11 years				
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16 years				
17 years				
18 years				
19 years				
20 years				
30 years				
40 years				
50 years				
60 years				