Participant Information Survey

We want to welcome you to our study and thank you for joining our study of Craniosynostosis, through your registration on our website: https://genetics.ucdmc.ucdavis.edu.

In order to study the environmental factors that may possibly cause craniosynostosis, we ask that you please complete the survey below. This online survey is divided into several sections and you can save your progress within each section. All responses to the survey will be kept confidential and shared only with the craniosynostosis collaborators (researchers) that are in the International Craniosynostosis Consortium (https://genetics.ucdmc.ucdavis.edu/icc.cfm).

You will also receive an email from us to coordinate sending you sample collection kits, for our study (Mouthwash and/or cheek swab).

Please don't hesitate to contact us with any questions by either by email (hs-boydlab@ucdavis.edu) or by calling 916-703-0454.

Participant's First Name _____

Participant's Middle Name _____

Participant's Last Name _____

Date of Birth _____

Gender ◯ Female ◯ Male

Diagnosis (Pick all that apply)
- ☐ Sagittal
- ☐ Metopic
- ☐ Right Coronal
- ☐ Left Coronal
- ☐ Bicoronal
- ☐ Right Lambdoidal
- ☐ Left Lambdoidal

Participant's Race: (check all that apply)
- ☐ Caucasian
- ☐ African American
- ☐ Asian
- ☐ American Indian
- ☐ Other

Other _____

Are you Hispanic? ◯ Yes ◯ No

Street Address _____

City _____

State _____

Zip Code _____

Primary Phone Number _____

Fax Number _____

E-mail _____

Mother's Information

Mother's First Name _____

Mother's Middle Name _____

Mother's Last Name _____

Mother's Date of Birth _____

Mother's Age at Conception _____

Mother's Race: (check all that apply)

- ☐ Caucasian
- ☐ African American
- ☐ Asian
- ☐ American Indian
- ☐ Other

Other _____

Mother's Ethnicity: Are you Hispanic? ◯ Yes ◯ No

Mother's Street Address _____

City _____

State _____

Zip Code _____

Primary Phone Number _____

Work Phone _____

Cell Phone _____

Fax Number _____

Email _____

Father's Information

Father's First Name _____

Father's Middle Name _____

Father's Last Name _____

Date of Birth _____

Age at Conception _____

Father's Race (Check all that apply)

- ☐ Caucasian
- ☐ African American
- ☐ Asian
- ☐ American Indian
- ☐ Hispanic
- ☐ Other

Other _____

Father's Ethnicity: Are you Hispanic? ◯ Yes ◯ No

Father's Street Address _____

City _____

State _____

Zip Code _____

Primary Telephone _____

Work Telephone _____

Cell Phone _____

Fax Number _____

Email Address _____

Siblings

Does the participant have brothers or sisters (siblings)? ◯ Yes ◯ No ◯ Don't Know

Sibling 1

Name _____

Gender ◯ Female ◯ Male

Date of Birth _____

Full Sibling? ◯ Yes ◯ No

Paternal Half Sibling? ◯ Yes ◯ No

Maternal Half Sibling? ◯ Yes ◯ No

Sibling 2

Name _____

Gender ◯ Female ◯ Male

Date of Birth _____

Full Sibling? ◯ Yes ◯ No

Paternal Half Sibling? ◯ Yes ◯ No

Maternal Half Sibling? ◯ Yes ◯ No

Sibling 3

Name _____

Gender ◯ Female ◯ Male

Date of Birth _____

Full Sibling? ◯ Yes ◯ No

Paternal Half Sibling? ◯ Yes ◯ No

Maternal Half Sibling? ◯ Yes ◯ No

Participant History

Where was the participant born? _____

Participant's Birth Weight _____
(Numbers only & 2 decimal places)

Participant's Birth Weight ◯ lbs ◯ kg

Birth Length _____
(Numbers only & 2 decimal places)

Birth Length ◯ in ◯ cm

Head Circumference _____

Head Circumference ◯ in ◯ cm

Apgar Score _____
(1min/5min)

Was the baby full-term? ◯ Yes ◯ No ◯ Don't Know

Born at how many weeks? _____

When was the mother's last period before the participant's birth? _____

How was the participant delivered?

◯ Vaginally, normal
◯ Vaginally, with forceps
◯ Vaginally, with vacuum extraction
◯ Vaginally, with a breech position
◯ C-section, due to size
◯ C-section, due to a breech position
◯ Other

Other, please explain:

_____

Are you aware of any placental or umbilical cord defects? ◯ No ◯ Yes ◯ Don't Know

Right after birth did the participant suffer from any of the following? If yes, please explain.

10a) Jaundice requiring treatment? ◯ No ◯ Yes ◯ Don't Know

Explain

_____

10b) Trouble with oxygenation (cyanosis) ◯ No ◯ Yes ◯ Don't Know

Explain

_____

10c) Blood sugar problems ◯ No ◯ Yes ◯ Don't Know

Explain

_____

10d) Breathing difficulty and/or suction required ◯ No ◯ Yes ◯ Don't Know

Explain

_____

10e) Other (describe):

_____

General Health History

11a) What is the participant's current age (years and months): _____

11b) What is the participant's current height _____

11b) What is the participant's current height ◯ in ◯ cm

11c) What is the participant's current weight _____

11c) What is the participant's current weight unit ◯ lbs ◯ kg

12) Participant's Diagnosis

- ☐ sagittal
- ☐ unicoronal left
- ☐ unicoronal right
- ☐ metopic
- ☐ unilambdoid left
- ☐ unilambdoid right
- ☐ multiple sutures
- ☐ Other

Please Explain

_____

Is participant syndromic? ◯ No ◯ Yes ◯ Don't Know

13) At what age was the diagnosis made? Please indicate the age in years and months (yy/mm): _____

14) Did the participant have a head CT? ◯ No ◯ Yes ◯ Don't Know

a) Age at diagnosis (age in years and months - yy mm) _____

b) Result _____

c) When and Where was the CT done? _____

d) Can you mail us a copy of the CT scan results? ◯ Yes ◯ No

15) Did the participant have other imaging studies (MRI etc.)? ◯ No ◯ Yes ◯ Don't Know

Please explain _____

16) Does the participant have other congenital anomalies? ◯ No ◯ Yes ◯ Don't Know

Please explain _____

17) Has the participant ever had a clinical genetics evaluation? ◯ No ◯ Yes ◯ Don't Know

a) Where _____

b) When _____

c) By whom (Contact Info)

_____

18) Has the participant ever had a chromosome analysis? ◯ No ◯ Yes ◯ Don't Know

a) Where _____

b) When _____

c) Results _____

19) Has the participant ever had surgery? ◯ No ◯ Yes ◯ Don't Know

20) Has the participant had a history of hearing problems? ◯ No ◯ Yes ◯ Don't Know

21) Has the participant had a history of vision problems? ◯ No ◯ Yes ◯ Don't Know

22) Has the participant had a history of headaches? ◯ No ◯ Yes ◯ Don't Know

23) Has the participant had a history of seizures? ◯ No ◯ Yes ◯ Don't Know

24) Has the participant had a history of torticollis? ◯ No ◯ Yes ◯ Don't Know

25) Has the participant ever had problems with any of the following:

25a) Skin Problems	◯ No	◯ Yes	◯ Don't Know
25b) Face/Skull	◯ No	◯ Yes	◯ Don't Know
25c) Brain	◯ No	◯ Yes	◯ Don't Know
25d) Eye	◯ No	◯ Yes	◯ Don't Know
25e) Heart	◯ No	◯ Yes	◯ Don't Know
25f) Lung	◯ No	◯ Yes	◯ Don't Know
25g) Kidney	◯ No	◯ Yes	◯ Don't Know
25h) Intestinal	◯ No	◯ Yes	◯ Don't Know
25i) Joints	◯ No	◯ Yes	◯ Don't Know
25j) Limb	◯ No	◯ Yes	◯ Don't Know
25k) Skeletal/Spinal	◯ No	◯ Yes	◯ Don't Know
25l) Other	◯ No	◯ Yes	◯ Don't Know

25l) Other Problems Explain

_____

26) Does the participant have any of the following developmental delays?

26a) Motor	◯ No	◯ Yes	◯ Don't Know
26b) Speech	◯ No	◯ Yes	◯ Don't Know
26c) Learning	◯ No	◯ Yes	◯ Don't Know
26d) Behavioral	◯ No	◯ Yes	◯ Don't Know

27) Please indicate when the participant was able to:

27a) Sit without being propped (years/months) _____

27b) Stand without holding on to anything (years/months) _____

27c) Speak 10 words(years/months) _____

27d) Speak in short sentences (years/months) _____

27e) Additional Information or Comments:

_____

28) If the participant is school age, is he or she in an age appropriate grade level?

◯ No ◯ Yes ◯ Don't Know

If no, please explain.

_____

29) Is the participant or has the participant been in special education programs?

◯ No ◯ Yes ◯ Don't Know

If Yes, please explain.

_____

30) If there is any additional information that you feel is relevant or may be helpful to the study, please enter here:

_____