1. Consent Form

Dear Participants,

• You are being asked to participate in a research study designed to investigate family and personal health history for persons with Craniosynostosis.

• The research procedures involve completing a survey about your medical history. You will be asked to answer questions regarding your family history and your medical and developmental history. The survey may take about 20 minutes to complete.

• Participation in this study is voluntary. There is no cost to you and will not be paid for your participation in this research. You may refuse to participate or discontinue your involvement at any time without penalty. You may choose to skip a question.

• All research data collected will be stored securely and safely. Any information that is obtained in connection with this study will remain confidential. If the results of this study are published, your name or any other personally identifiable information will not be used at any
time.

• The research team and authorized UCI personnel may have access to your study records to protect your safety and welfare. Any information derived from this research project that personally identifies you will not be voluntarily released or disclosed by these entities without your separate consent, except as specifically required by law.

• If you have any comments, concerns, or questions regarding the conduct of this research please contact the researchers listed at the bottom of this form.

If you are unable to reach the researchers listed on this form and have general questions, or you have concerns or complaints about the research, or questions about your rights as a research subject, please contact the UCD IRB Administration at (916) 703-9151 or write to IRB Administration, CRISP Building, Suite 1400, Room 1429, 2921 Stockton Blvd., Sacramento, CA 95817.

Thank you,

Simeon Boyd, MD
sboyd@ucdavis.edu

I agree to complete this survey.

- ○ Yes
- ○ No

2. Sibling Information

Does the patient have brothers or sisters (siblings)?

- Yes
- No

3. Sibling Information

For each sibling please list their gender, age, and whether they are a full or half sibling. If a half sibling, please identify if paternal or maternal half sibling.

Sibling 1	
Sibling 2	
Sibling 3	
Sibling 4	
Sibling 5	
Sibling 6	
Sibling 7	
Sibling 8	
Sibling 9	
Sibling 10	

4. Sibling Information

For each sibling please past and present medical issues.

Sibling 1

Sibling 2

Sibling 3

Sibling 4

Sibling 5

Sibling 6

Sibling 7

Sibling 8

Sibling 9

Sibling 10

5. Biological Children Information

Does the patient have biological children?

- Yes
- No

6. Biological Children Information

For each biological child of the patient please list their gender and age.

Child 1

Child 2

Child 3

Child 4

Child 5

Child 6

Child 7

Child 8

7. Biological Children Information

For each child of the patient please past and present medical issues.

Child 1

Child 2

Child 3

Child 4

Child 5

Child 6

Child 7

Child 8

8. Family History

Does the patient have any relatives born with any birth defects not identified in the above responses? (include aunts, uncles, grandparents, and cousins)

- ○ Yes
- ○ No

9. Family History

For each affected relative please list their gender, age, relationship to the patient, and their medical concern.

Relative 1

Relative 2

Relative 3

Relative 4

Relative 5

Relative 6

Relative 7

Relative 8

Relative 9

Relative 10

10. Reproductive Information

Has the patient, their parents, or their siblings had infertility problems, pregnancy losses, or prematurity?

- Yes
- No

11. Reproductive Information

Please explain and specify your answer to the above question. Include relationship to the patient.

12. Patient's Medical History

Review of Systems: Please indicate if the patient has ever had problems with any of the following

	Yes	No
Fatigue	○	○
Unexplained weight gain or loss	○	○
Chronic Fever	○	○
Chronic Ear Infections	○	○
Hearing Problems	○	○
Swallowing Problems	○	○
Nasal Congestion	○	○
Palate issues	○	○
Heart problems	○	○
Chest pains	○	○
Palpitations	○	○
Breathing problems	○	○
Chronic Cough	○	○
Chronic vomiting	○	○
Chronic constipation	○	○
Chronic Diarrhea	○	○
Abdominal pain	○	○
Chronic Jaundice	○	○
Kidney or bladder infections	○	○
Incontinence	○	○
Convulsions or seizures	○	○
Headaches	○	○
Muscle weakness	○	○
Growth abnormalities	○	○
Hormonal concerns	○	○
Emotional or behavior problems	○	○
Psychiatric problems	○	○
Skin abnormalities	○	○
Birth Marks	○	○
Prolong bleeding /easy bruising	○	○
Visual Problems	○	○
Bone problems or osteoporosis	○	○

Behavioral concerns	○	○
Learning disabilities	○	○
Speech abnormalities (ex. Nasally speech)	○	○

Please explain yes responses

13. Developmental Assessements

Has the patient ever had a developmental assessment?

- ○ Yes
- ○ No

14. Developmental Assessements

Please identify type of developmental assessment and results.

15. Educational Information

Does the patient follow an adapted academic curriculum program in school?

- ○ Yes
- ○ No

16. Educational Information

Please describe type of adapted academic curriculum

17. Hospitalizations

Has the patient ever been hospitalized?

- ○ Yes
- ○ No

18. Hospitalizations

Please describe when, for how long, and reason for each hospitalization.

19. Surgeries

Has the patient ever had any surgeries, or have any surgeries planned?

- ○ Yes
- ○ No

20. Surgeries

Please describe when and why. If surgeries has already occurred, the outcome of each surgery.

21. Genetic Information

Has the patient been diagnosed with a genetic syndrome?

- ○ Yes
- ○ No

22. Genetic Information

What is the name of the genetic syndrome?

23. Genetic Information

Has the patient had genetic testing performed?

- ○ Yes
- ○ No

24. Genetic Information

What genetic testing was performed (What genes were tested?) and what were the results of those test?

25. Contact Information

Please update your current contact information.

Address:

Address 2:

City/Town:

State:

ZIP:

Country:

Email Address:

Phone Number:

Do you have any other comments or updates that you would like to share with our research team?