

# ADRENAL Patient Questionnaire

Thank you for taking your time to contribute to our research. Please fill in the form below to the best of your knowledge.

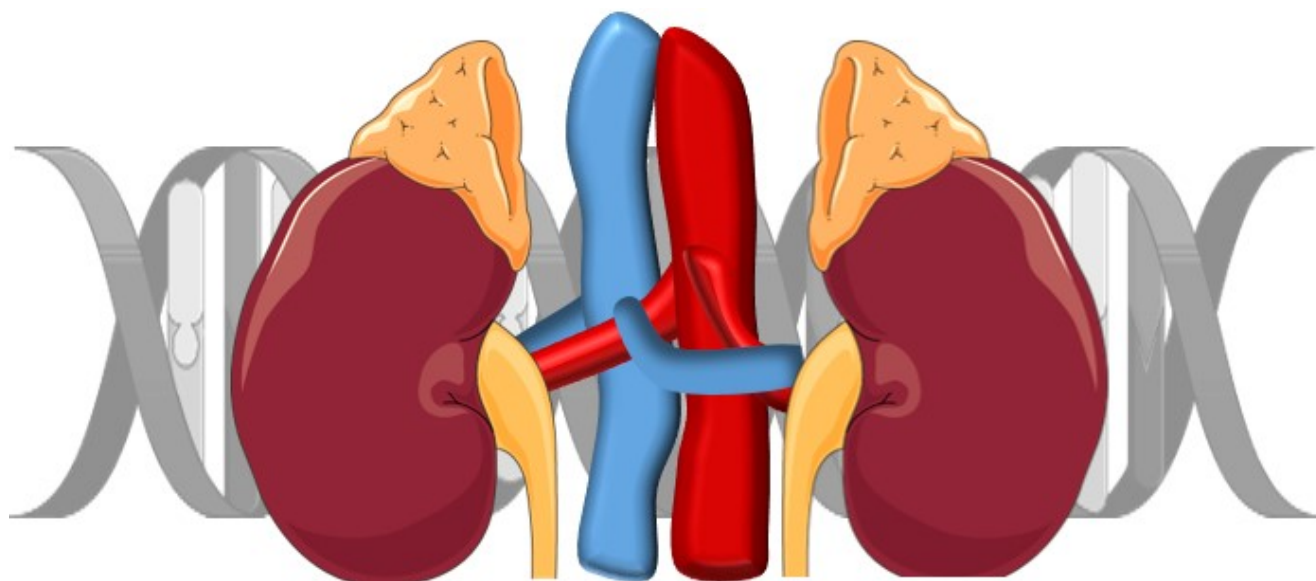
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## Physician Information

Survey Completion Date \_\_\_\_\_

Date Calculation \_\_\_\_\_



# A.D.R.E.N.A.L

Referring Physician \_\_\_\_\_

Physician's Email Address \_\_\_\_\_

Lead Consultant \_\_\_\_\_

Institute Address \_\_\_\_\_  
\_\_\_\_\_

Contact Number \_\_\_\_\_

Date of Next Consultation \_\_\_\_\_

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**Patient Data**

Record for:

- Affected Patient
- Non-affected Family Member

Study ID

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Hospital Number

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First Name

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Middle Name

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Last Name

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Date of Birth

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Gender

- Male
- Female

Ethnicity

- Non-Finnish European
- Finnish
- African
- Latino
- South Asian
- Ashkenazi Jewish
- East Asian
- Other

Details

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Country of Birth

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Clinical Diagnosis

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**Auxology Data**

Birth Weight (kg) \_\_\_\_\_

Birth Length (cm) \_\_\_\_\_

Gestational Age (weeks) \_\_\_\_\_

Current Height (cm) \_\_\_\_\_

Current Weight (kg) \_\_\_\_\_

Date of Assessment \_\_\_\_\_

Age at Assessment \_\_\_\_\_

Maternal Height (cm) \_\_\_\_\_

Maternal Weight (kg) \_\_\_\_\_

Paternal Height (cm) \_\_\_\_\_

Paternal Weight (kg) \_\_\_\_\_

Affected Siblings  Yes  
 No

Affected Sibling Information

\_\_\_\_\_  
(Please give details)

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## Puberty

Pubertal Status

- Prepubertal
- Pubertal

Age of Onset of Puberty

\_\_\_\_\_

Pubertal Staging

\_\_\_\_\_

Evidence of Dysregulated Puberty

- Yes
- No

Details

\_\_\_\_\_

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## History

Presenting Complaint

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Age of Onset

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Consanguinity

- Yes
- No

Parents Relationship

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Please Upload a Family Tree

Hyperpigmentation

- Yes
- No

Learning Difficulties

- Yes
- No

Details

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Disordered Sexual Differentiation

- Yes
- No

Details

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Significant Events

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Additional Conditions or Features

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**Investigations**

Bone Age and Chronological Age at Time of Assessment \_\_\_\_\_

Cortisol Units

- 
- ug/dL
- 
- 
- nmol/l

Cortisol Level at Diagnosis \_\_\_\_\_

Cortisol Level at Diagnosis \_\_\_\_\_

Normal Cortisol Range \_\_\_\_\_

ACTH Units

- 
- pg/ml
- 
- 
- pmol/l

ACTH Level at Diagnosis \_\_\_\_\_

Calculated ACTH Level \_\_\_\_\_

Normal ACTH Range \_\_\_\_\_

Renin Units

- 
- pg/mL
- 
- 
- pmol/L

Direct Renin Concentration \_\_\_\_\_

Renin Calculation \_\_\_\_\_

Normal Renin Concentration Range \_\_\_\_\_

Renin Activity (ng/mL/h) \_\_\_\_\_

Aldosterone Units

- 
- ng/dL
- 
- 
- pmol/L

Aldosterone Level (serum) \_\_\_\_\_

Aldosterone Calculated \_\_\_\_\_

Normal Aldosterone Range \_\_\_\_\_

DHEAS Units

- 
- ug/dL
- 
- 
- umol/L

DHEAS Level \_\_\_\_\_

DHEAS Calculated \_\_\_\_\_

Normal DHEAS Range \_\_\_\_\_

Androstenedione Units

- 
- ng/dL
- 
- 
- nmol/L

Androstenedione Level \_\_\_\_\_

Androstenedione Calculated \_\_\_\_\_

Normal Androstenedione Range \_\_\_\_\_

17-OHP Units

- 
- ng/dL
- 
- 
- nmol/L

17-OHP Level

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17-OHP Calculated

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Normal 17-OHP Range

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Additional Biochemistry of Note

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Synacthen Test Performed?

- Yes
- No

Synacthen Test Results

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## Imaging

Adrenal Imaging Performed

- Yes
- No

Details

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Pituitary Imaging Performed

- Yes
- No

Details

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**Treatment**

Steroid Replacement

- Hydrocortisone
- Other

Hydrocortisone Replacement Dose

\_\_\_\_\_

Alternative Steroid Replacement Regime

\_\_\_\_\_

Mineralocorticoid Deficiency

- Yes
- No

Fludrocortisone Replacement Dose

\_\_\_\_\_

Other Notes Regarding Medication

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**Sample Collection**

Blood/DNA Collected?

- Yes
- No

Family Blood/DNA Collected?

- Yes
- No

Family Member DNA

- Mother
- Father
- Affected Brother
- Brother
- Affected Sister
- Sister
- Other

Please give details

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Other Comments

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(Any other information deemed important)

Please upload anything of importance

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**Laboratory Use Only - Please Proceed to Submit**

Please upload anything of importance (consent form)

Please upload anything of importance

Sample Location \_\_\_\_\_

Candidate Genes Sequenced

- MC2R - Forward
- MC2R - Reverse
- MRAP - Exon 3
- STAR - Exon 4
- STAR - Exon 5
- CYP11A1 - Exon 5

Mutation Solved?

- Yes
- No

Mutation Diagnosis \_\_\_\_\_

Sent for WES

- Yes
- No

Mutation Solved?

- Yes
- No

Mutation Diagnosis \_\_\_\_\_