**NephCure-PARASOL Grant Application**

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| **INSTRUCTIONS** | | | | | | | |
| **Grant submission:** | | | | | | | |
| All applications should be compiled into a single pdf format document that can be read using the Adobe Reader or Acrobat application. Formal grant applications should be emailed to Rebecca Cook, Director, Strategic Operations at [rcook@nephcure.org](mailto:rcook@nephcure.org). Please place “PARASOL grant applic/Your last name” in the subject line. A receipt will be provided on the following day. | | | | | | | |
| **Formatting requirements:** | | | | | | | |
| Applicants must the following application template and must be written in English language. Applications that fail to comply with this format will be returned to the applicant without review. | | | | | | | |
| **Principal Investigator Information:** | | | | | | | |
| Name: | |  | | | Degree(s): |  | |
| Position Title: | |  | | | | | |
| Department: | |  | | | | | |
| Institution: | |  | | | | | |
| Email Address: | |  | | | | | |
| **Registry/Dataset Information:** | | | | | | | |
| Name/Title: | | |  | | | | |
| Overseeing institution for data use agreement: | | |  | | | | |
| Ethics (IRB/REC) approval status to allow sharing of data\*: | | | Ethics approval complete  Ethics approval pending | | | | |
| \*Evidence of IRB approval is necessary prior to issuance of notice of award | | | | | | | |
| **ADMINISTRATIVE OFFICIAL TO BE NOTIFIED IF AWARD IS MADE** | | | **OFFICIAL SIGNING FOR APPLICANT ORGANIZATION** | | | | |
| Name |  | | Name |  | | | |
| Title |  | | Title |  | | | |
| Address |  | | Address |  | | | |
| Tel: |  | | Tel: |  | | | |
| E-Mail: |  | | E-Mail: |  | | | |
| 14. APPLICANT ORGANIZATION CERTIFICATION AND ACCEPTANCE: I certify that the statements herein are true, complete and accurate to the best of my knowledge, and accept the obligation to comply with Public Health Services terms and conditions if a grant is awarded as a result of this application. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties. | | | SIGNATURE OF OFFICIAL NAMED ABOVE:  *(In ink. “Per” signature not acceptable.)* | | | | DATE |

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| **Registry/Dataset Summary:** | |
| Description (300 words or less) which includes the following:   * recruitment centers/catchment area, * dates of study, * retrospective vs prospective study design, * age span, * strengths and limitations |  |
| Data Coordinating Center |  |
| Funding source | Federal/National  Industry  Foundation  Philanthropy  Other, specify: |
| How will data be contributed? | Limited dataset to be shared (DUA needed)  Anonymized dataset to be shared (DUA needed)  In house analysis to be performed following receipt of central code with aggregate results returned (DUA not needed) |
| Anticipated month and year that data will be ready for submission to the PARASOL data coordinating center (additional comments allowed). | \_\_\_\_\_\_\_\_ /2024  Month  Comments: |
| Data collection methodology and follow up description (100 words or less) |  |
| Eligibility criteria of participants |  |
| How is diagnosis of FSGS assigned within cohort? |  |
| Complete the following table:   |  |  |  | | --- | --- | --- | | **FSGS Cohort Characteristics** | | | | # biopsy proven or monogenic FSGS subjects in cohort | |  | | # FSGS subjects in cohort with\*   1. index UPCR≥1 g/g at or after biopsy/diagnosis (or up to 3 months prior to biopsy/diagnosis) AND 2. index eGFR≥30 ml/min/1.73m2. eGFR measurement must be within ±3 months from index UPCR AND 3. ≥1 UPCR measurement 6-24 months after index date AND 4. No kidney failure events prior to the first observed UPCR>6 months post-index date | |  | | **Are you able to report/share the following data elements:** | | | | Age | Yes  No  Not currently but it could be collected | | | Sex | Yes  No  Not currently but it could be collected | | | Racial or ethnic minority | Yes  No  Not currently but it could be collected | | | UPCR\* | Yes  No  Not currently but it could be collected | | | eGFR or elements of | Yes  No  Not currently but it could be collected | | | Length of follow up | Yes  No  Not currently but it could be collected | | | Kidney failure events | Yes  No  Not currently but it could be collected | | | Death (all cause) | Yes  No  Not currently but it could be collected | | | Medication exposure | Yes  No  Not currently but it could be collected | | | Blood pressure | Yes  No  Not currently but it could be collected | | | Kidney pathology | Yes  No  Not currently but it could be collected | | | Kidney genetic results | Yes  No  Not currently but it could be collected | |   \*UACR or total urine protein or total urine albumin may be used in place of UPCR. | |

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| **Budget Justification:** |
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| **Budget:** |
| Budget should be attached as final page using the NIH Form 398 application Form Page 4 (a modular budget should not be used). <http://grants1.nih.gov/grants/funding/phs398/phs398.html> |