**NephCure-PARASOL Grant Application**

|  |
| --- |
| **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. 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      |

|  |
| --- |
| **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 MonthComments:  |
| 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.  |

|  |
| --- |
| **Budget Justification:** |
|  |
| **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>  |