

**Seizures and Epilepsy in Children with PKS
Family Questionnaire
(June 25, 2009)**

Child's name:

Date of birth:

Definite diagnosis of PKS (confirmed by chromosome testing)? YES NO

1. Has your child ever been diagnosed with epileptic seizures? YES NO
2. If, answer is NO, do you suspect that your child has or has/had epileptic seizures: YES NO
3. (If answer to both of the above questions is "NO" you can skip the rest of the questionnaire)
4. At what age did your child first have seizures:
5. Has your child had more than one type of seizure? YES NO
6. What type(s) of seizures has your child had (do not worry if you do not know these terms; only answer those for which you are certain)?
 - Generalized tonic-clonic ("grand-mal")
 - Absence ("petit-mal")
 - Atypical absence (a worst type of "petit-mal")
 - Simple Partial
 - Complex partial
 - Infantile Spasms
 - Myoclonic
 - Generalized tonic
 - Drop attacks
 - Other (please specify):

7. My child's seizures occur or have occurred:

- During the day only.
- At night only.
- Both during day and night

8. At worst, how often do your child's seizures occur:
- More than once a day (specify average number per day): ____ per day.
 - Less than once a day but more than once a week (specify average number per week): ____ per week
 - Less than once a week but more than once a month (specify average number per month): ____ per month
 - Less than once a month but more than once a year (specify average number per year): ____ per year
 - Other (specify how often):
9. Do your child's seizures tend to cluster together (occur in groups with longer periods in between groups of seizures)? YES NO
- If Yes, about how many seizures occur per group?
 - If Yes, how long will a group of seizures go on for?
10. How long do your child's seizures typically last? (if child has more than one type please specify average length of each type):
11. Has your child ever had a seizure lasting more than 15 minutes or seizures occurring back to back without recovery for more than 15 minutes? YES NO
12. If yes, how many times has this happened?
13. Has your child had to be hospitalized specifically for the treatment of seizures? YES NO
14. If yes, how many times?
15. Are there any specific triggers for your child's seizures? YES NO
16. If yes, what are those triggers?

17. Which of the following medications/treatments has your child received for the treatment of seizures?

- Phenytoin (Dilantin)
- Phenobarbital
- Carbamazepine (tegretol, carbatrol)
- Oxcarbazepine (trileptal)
- Valproic acid (depakote, depakene)
- Ethosuximide (zarontin)
- Topiramate (topamax)
- Lamotrigine (lamictal)
- Zonisamide (Zonegran)
- Levetiracetam (Keppra)
- Clonazepam (klonopin)
- Gabapentin (neurontin)
- Tiagabine (gabatril)
- ACTH (Acthar gel; Adrenocorticotrophic hormone)
- Prednisone
- Vagal nerve stimulator (VNS)
- Brain surgery
- Vitamins, supplements or "homeopathic" agents (please specify):

- Other:

18. Which if any of the above medications/treatments has been most helpful for your child?

19. Does your child still have seizures? YES NO

20. If YES, what is the longest period in your child's life during which she/he has not had seizures (since the seizure first showed up)?

21. If answer to question 19 is NO,

- a. How long has your child been free of seizures?
- b. Does your child still take medication for seizures (and if so which ones): YES NO. Which ones?

22. If your child is now free of seizures and no longer taking medication, how long has he/she been free of seizures without taking medication for seizures?
23. Do you know your child's IQ or measured IQ score? YES NO
24. If yes, please provide number here:
25. If no, can you estimate your child's developmental age? (for example, my child functions like a 4 year old, or like a 2 year old).
26. Could you please describe your child's seizures in your own words? (If more than one type, please describe each type separately):

27. Has your child had one or more EEGs (Electroencephalograms)? YES NO

a. If YES, how many, when and what were the results if you know them?

28. Has your child had one or more MRI scans of the brain? YES NO

a. If YES, how many, when and what were the results if you know them?

29. Would you be willing to have your child's neurologic records sent to us for us to review? YES NO

30. Would you be willing for us to contact you by phone to obtain additional information? YES NO

31. If yes, what are the best phone number(s) and time(s) to call:

Thank you very much for your time in answering these questions. We appreciate your information and hope this will assist doctors and families in better understanding seizures in children with PKS. Please add anything else you believe could be important for us to know.

Sincerely, Meghan Candee, MD; Francis Filloux, MD, John Carey, MD and Ian Krantz, MD