

# Beatrix Children's Hospital

University Medical Centre Groningen  
P.O. Box 30 0019700 RB Groningen, The Netherlands

**University Medical Center Groningen**  
**Department of Pediatrics**

Head of department Prof. dr. mr. A.A.E. Verhagen

Division Metabolic diseases in children

Head of division Prof. dr. F.J. van Spronsen

To  
Mr Fergus Woodcock  
Chairman PKU Association of Ireland

Phone +31 (0)50 361 4147

Fax +31 (0)50 361 1671

Internal ZIP code CA33

Enclosure(s)

Ref. 17.023/ FJvS/ed

Date October 18<sup>th</sup>, 2017  
Re. Experiences with PKU

Dear sir,

The Irish PKU association asked me to write about the experiences with PKU.

I have for some 30 years of experience treating patients for PKU, a serious condition which -if left untreated- can lead to severe intellectual and physical disability with seizures, psychiatric issues, necessitating continued help. Dietary therapy has been successful by preventing the severe mental retardation but still outcome of these patients is not completely comparable to their siblings even knowing the life of the whole family is changed by the disease of the child. One of the important reasons is that the dietary treatment is extremely challenging not only for the patient but also for the whole family. Kuvan, at present being the only pharmaceutical treatment for PKU, not only helps to further improve the intellectual and social outcome of patients but also improves patients quality of life by lessening the dependence on dietary therapy.

Yours sincerely,

  
Prof dr Francjan J van Spronsen,  
Pediatrician Metabolic Diseases  
Head of the division of Metabolic Diseases  
Chair of the Scientific Advisory Committee of the ESPKU and Allied Disorders



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