



European
Reference
Network

for rare or low prevalence
complex diseases

 Network

Intellectual Disability
and Congenital
Malformations (ERN ITHACA)

NHS

Manchester University
NHS Foundation Trust

ERN ITHACA: Professionals and Patients Working Together

Janet Williams; Independent Fetal Anticonvulsant Trust

Jill Clayton-Smith; Manchester University Hospitals NHS Trust



I·T·H·A·C·A

Disclaimer

Neither Janet Williams nor Jill Clayton-Smith have any conflict of interest to declare in relation to this presentation.

Setting The Scene

Janet's Story

Developed epilepsy and treated with the antiepileptic drug sodium valproate
2 sons, took medication during both pregnancies



Realisation of problems and search for diagnosis and recognition for FVS

Setting up of support groups

Jill's Story

Clinical geneticist , interest in syndrome diagnosis

Recognition of problems associated with VPA exposure early 1990s.

First met Janet in clinic shortly after

Set up prospective follow-up study



724

J Med Genet 1995;32:724-727

Syndrome of the month

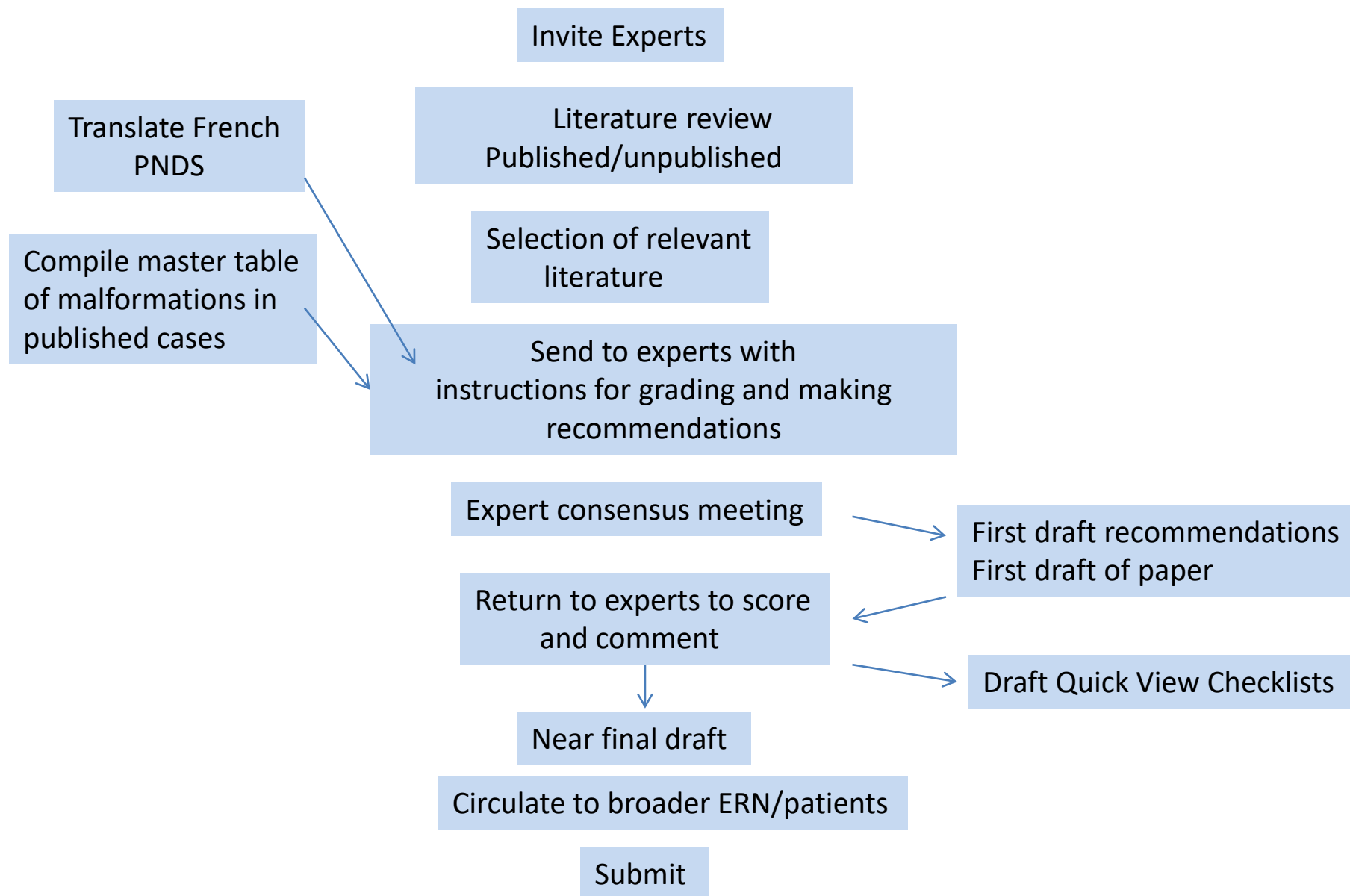
Fetal valproate syndrome

Working Together Pre-ERN

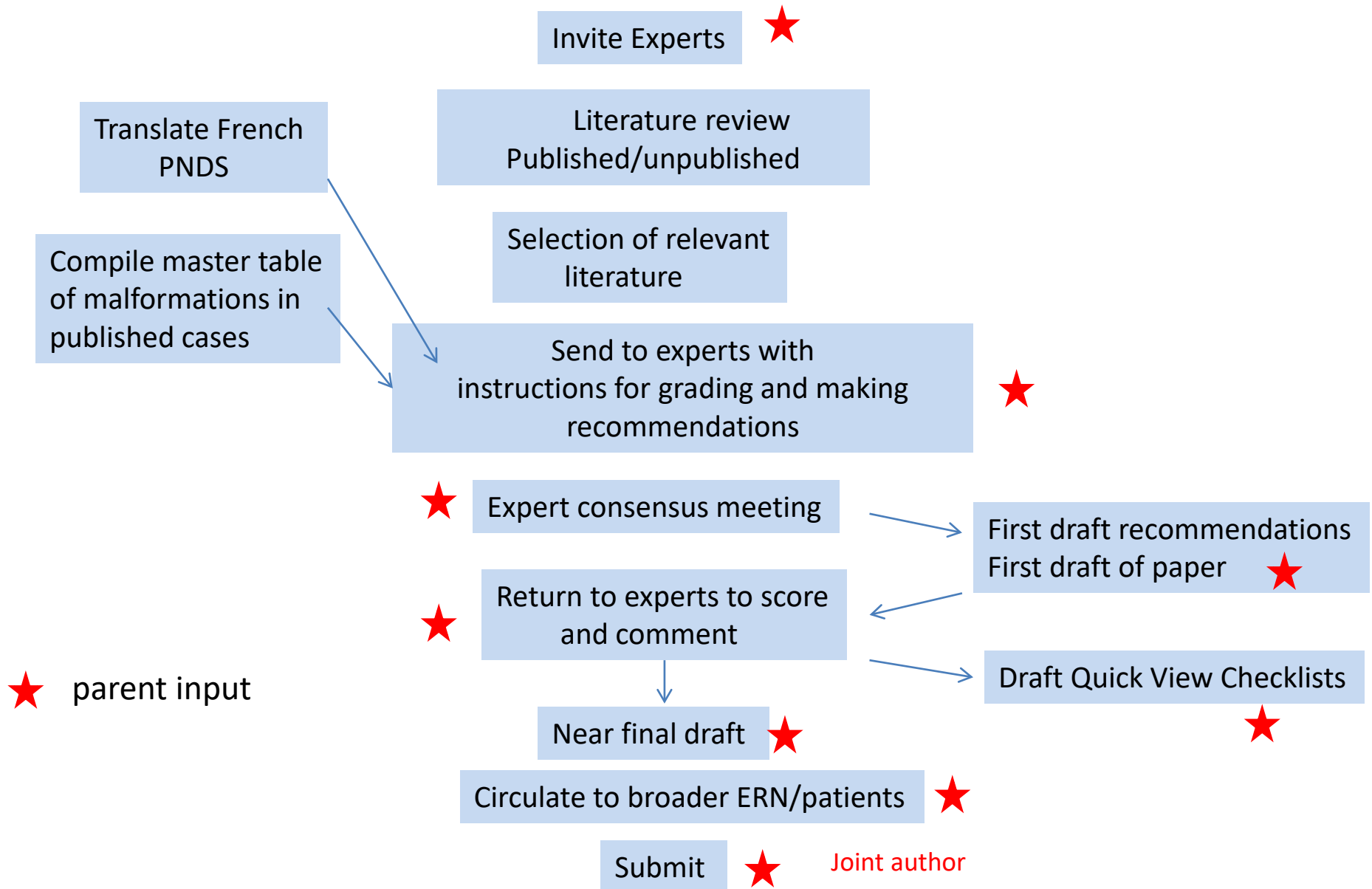
- At hospital appointments
- Production of Patient Information
- Patient Support Group meetings
- Independent Expert Groups
- Long term follow-up study
- Recruitment to other research studies
- Dissemination of information



Our ERN Initiative: Guidelines For Fetal Valproate Syndrome

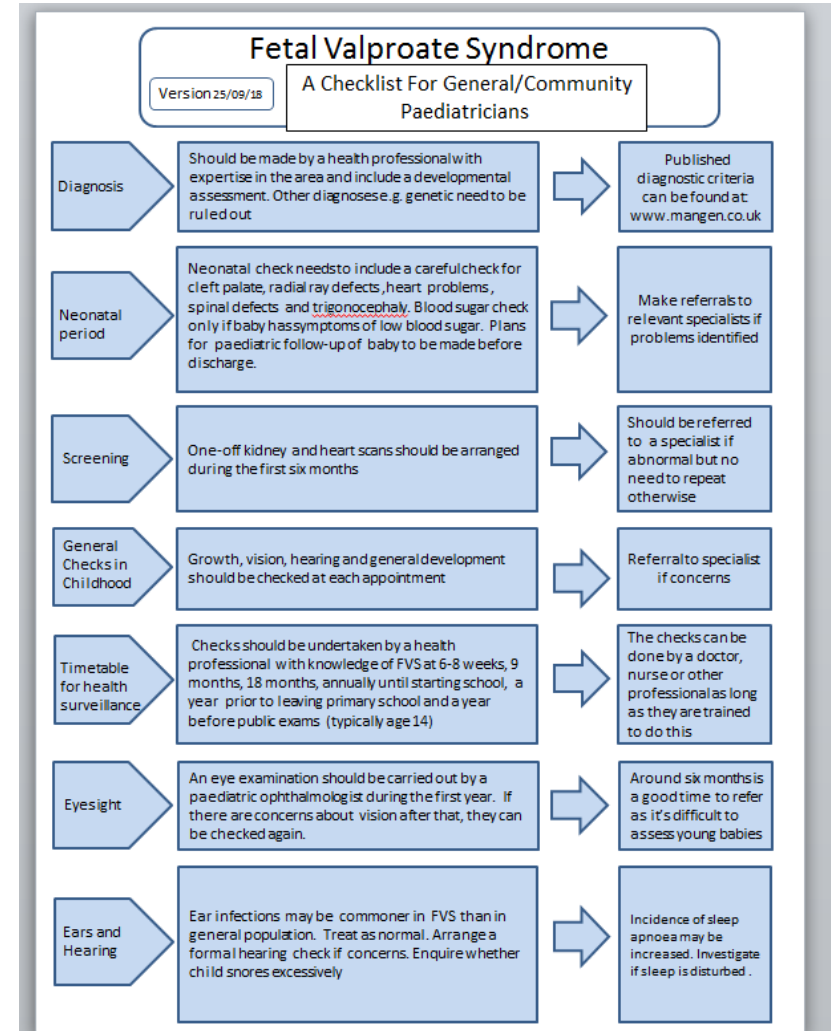


Guidelines For FVS; Patient Involvement



How It Made A Difference

- One of most engaged members of group
- Easily as well read as other members
- Able to put forward a broad patient perspective, not focus on personal issues
- Comments on feasibility
- Ideas re supplementary sheets



Lessons We Learned

- Learned about guideline development and felt it was a very thorough process with easy to understand points and explanations.
- I felt it was an open discussion allowing patient experts to give their input and their experiences
- Valued member of the team. All my points and suggestions were listened to and well accepted within the group
- There was an acceptance of the problems that FVS caused the child and family members
- Informed patients bring added knowledge and value to the process
- Patients know some systems eg education and social care better than a lot of professionals
- Care plans are no good if they are not feasible for families and if they don't reach the people you want them to
- Whole process felt relaxed; No "them and us." Very rewarding and makes you look forward to more initiatives like this

Recommendations For And Challenges To Building Strong Patient/Professional Relationships

- We need to be accessible to each other whilst also respecting each other's busy roles
- Patients should be empowered to have the confidence to take on key roles and to challenge professionals
- All information should be shared between patients and professionals (not just selected information)
- Patients views should hold just as much weight as professionals
- Adequate funding should be provided for PPI activity – it's expensive.
- Some patients may need training in how to see the bigger picture and some professionals may need training in how to communicate better with patients
- Work in an equal partnership and respect each other

Acknowledgements

- CHAFEA
- DG SANTE
- INFAC
- Patients and Families
- ERN Guideline Group
- Myfanwy Rawson
- Michael Smith

