The Queen Elizabeth Hospital NHS
King's Lynn
NHS Foundation Trust

REPORT TO THE BOARD OF DIRECTORS (IN PUBLIC)

RESPONSIBLE DIRECTOR:	REPORT FOR:		IMPACT ON BUSINESS:		
Catherine Morgan Director of Nursing	Decision		High	Med	Low
	Discussion	✓	✓		
	Information	✓			
LEAD MANAGER:	**REPORT TYPE:**		**BAF REFERENCES & RAG:**		
Claire Roberts Associate Director of Patient Experience	Strategic				
	Operational	✓			
	Governance	✓	**RELATED WORK: (PREVIOUS PAPERS TO COMMITTEE)**		
PEER ASSIST:	**PEER REVIEW:**				
CQC Domain: (safe, caring, effective, responsive, well-led)	All				

Meeting Date: 24th November 2015

Report Title: Patient Story

PURPOSE:
To provide the Board with the context of today's 'Patient Story' so that the Board appreciates the background to the story.
SUMMARY:
Please see attached summary

RISK ASSESSMENT (CROSS-REFERENCE WITH RISK REGISTER WHERE APPROPRIATE):

Strategic / External	Operational/ Organisational	Financial	Clinical	Legal/ Regulatory	Reputational / Patient Experience
	✓		✓		✓

RECOMMENDATION/S:
For information

Patient Story

Board of Directors meeting 24 November 2015

The Patient Story today is presented by Mrs. Valerie Crewe. She is accompanied by her husband, Peter, and one of our Clinical Trials Nurses, Tracy Fuller. Mrs. Crewe has been a patient at this hospital since 2010 when she received the unwelcome and unexpected news that the atypical symptoms that she had been experiencing meant that in fact she was actually suffering from Parkinson's disease.

Since that time Mr. and Mrs. Crewe have endeavoured to find out as much as they can about the disease and have looked for ways to control the debilitating symptoms that she experiences on a daily basis. This led them to becoming active members of the local branch of the Parkinson's Disease Society and when the opportunity arose, Mrs. Crewe was keen to be part of a national research trial called Proband.

Mrs. Crewe volunteered today to come and talk to the Board about what her experience has been as a long term patient of the Neurology Department and more especially what it has been like to be involved in a research trial looking at Parkinson's disease. In the last five years since her diagnosis she has in turn been cared for by all three neurology consultants and she refers to them rather affectionately as the "the three B's", namely Dr. Brown, Dr. Barker and Dr. Buttery.

The research study required a three year period of commitment but she will tell you herself what that has involved. For information the purpose of the study is summarised by the UK Clinical Research Network Study Portfolio as follows:

'The principal research objective is to prospectively record the clinical features and progression rate of patients with early Parkinson's disease, in order to stratify patients according to different expression of the disease, relating to motor severity, response to anti-Parkinson medication, and the presence of non-motor features. These observations will be assessed in relation to the presence of known gene mutations linked to the condition (although these only affect a total of 5% of patients with Parkinson's disease). First degree relatives of patients with Parkinson's disease will also be studied, to determine early features of presentation, before the typical signs of tremor, stiffness and slowness develop – these include symptoms of constipation, depression, loss of sense of smell and sleep disturbance.'

Mr. and Mrs. Crewe and Tracy are all happy to answer any questions that you may have.