

## The Katharine Dormandy Haemophilia Centre and Haemostasis Unit A history.

A personal reminiscence developed from conversations with Peter Kernoff, Peggy Britten, Patricia Lilley, Riva Miller, Clifford Welch, Victor Hoffbrand together with my own memories and perceptions.

**1964** Professor Hardisty, then head of the department of Haematology at Great Ormond Street encouraged Katharine Dormandy to take up the post of Senior Lecturer in Haematology at Lawn Road Hospital Hampstead, part of the Royal Free Hospital, then located at Gray's Inn Road. Initially there were 4 patients. The beds were at the end of a ground floor ward adjacent to the car park.

**1966** Katharine Dormandy began the manufacture of cryoprecipitate in the first floor haematology laboratory. This was later dispensed from a deep-freeze in a side room attached to the ward. In **1970** the manufacture of cryoprecipitate was later taken over by the North London Transfusion Service. Katharine Dormandy pioneered home treatment using cryoprecipitate in **1971**.

In **1965** the Haemophilia Society donated a large caravan to provide office space for Katharine Dormandy and her research assistant studying the medical and schooling problems of haemophilic boys. The publication: Britten et al *BMJ* 1966; 2: 224-228, reported on this research. The caravan remained a prominent land-mark at Lawn Road until demolition in **1973**.

Katharine Dormandy completed an MD on Von Willebrand's Disease and one of the patients who featured in this (MM) is still alive. This patient had type 3 VWD and had a hysterectomy under cover of cryoprecipitate.

The planned move of the Royal Free from Gray's Inn Road to a new hospital on the Lawn Road site (finally opened in **1978**) alerted Katharine Dormandy to the possibility of achieving a purpose built haemophilia centre within the medical school. A generous financial contribution was obtained from the father of one of the haemophilic patients, Mr Laurence Knight. Unfortunately, Katharine Dormandy was unable to work in the centre she had achieved – she had **GRO-A** She was able to appoint the first director and new consultant – Dr Peter Kernoff in **1977**.

Dr Ted Tuddenham was appointed Senior Lecturer in **1977** by the new Professor of Haematology, Victor Hoffbrand, following the death of Katharine Dormandy.

**The Katharine Dormandy Trust** was set up to achieve the building of the new centre opened in **1978**.

After his appointment, Peter Kernoff found that the financial donation of Laurence Knight had 'gone astray' and after much 'detective' work, it was found that bonds had been purchased using this money by the Royal Free. Peter Kernoff secured these monies back to the Katharine Dormandy Trust.

Subsequently the Katharine Dormandy Trust supported much of the research and infrastructure of the centre achieving all of Katharine Dormandy's aims for haemophilia care culminating in an established chair of haemophilia.

The Katharine Dormandy Trust provided £500,000 for the extension, opened in **1994**, to provide office space and laboratory space – the Peter Kernoff building and Clive Knight laboratories.

The Katharine Dormandy Trust under the chairmanship of Clifford Welch was instrumental in negotiating the Katharine Dormandy Chair of Haemophilia with the first appointee in **2006**. The Katharine Dormandy Trust was disbanded in **2007**.

## **Katharine Dormandy Haemophilia Centre and Haemostasis Unit**

(List compiled by Professor Christine Lee 12.XII.14, revised February 15)

### *Postgraduate students supervised by Professor Christine Lee*

1. Professor Seng Lim, **MD** 1988-91, (Head of department University of Singapore)
2. Dr Paul Telfer, **DM** 1991-1994, (consultant haematologist at Bart's)
3. Professor Caroline Sabin **PhD** 1991-1995, (Professor Department of Epidemiology, Royal Free UCL)
4. Dr Helen Devereux **PhD** 1992-1996, (sadly she has died)
5. Dr Dale Owens **PhD** 1992-1997, (teaching prep school boys in science, Brisbane Australia)
6. Dr Ricarda Steinbrecher, **PhD** 1992-1994 (whereabouts unknown)
7. Dr Gaynor Miller, **PhD** 1993-1997 (postgraduate in California)
8. Dr Alexander Miners, **PhD** 1995-1998 (Reader London School Hygiene and Tropical Medicine)
9. Dr Rezan Kadir, **MD** 1995-1998 (Reader UCL and Consultant Obstetrician Gynaecologist Royal Free)
10. Dr Ionna Nitu-Whalley, **MD** 1998-2001 (Consultant Haematologist Cambridge)
11. Dr Thynn Thynn Yee, **MD** 1998-2001 (Associate Specialist Haemophilia Centre, RFH)
12. Dr Esteban Herrero, **PhD** 1998-2001 (whereabouts unknown UCL?)
13. Dr Jenny McIntosh, **PhD** 2000-2004 (postgraduate member of Professor Nathwani's research group UCL)
14. Dr Karen Beeton, **PhD** 2003-2006 (Reader University of Hertfordshire)
15. Dr Niamh O'Connell, **PhD** 2001-2009 (Consultant Haematologist, St James Hospital, Dublin)
16. Mr Haroon Mann, **MD** 2005-2009 (Consultant Orthopaedic Surgeon with special interest in haemophilia Royal Free Hospital)
17. Miss Claudia Chi, **MD** 2005-2009 (Consultant Obstetrician Gynaecologist and Senior Lecturer University of Singapore)
18. Miss Ashwani Kulkarni, **MD** 2006-2010 (Consultant Obstetrician Gynaecologist Royal Northern Hospital)

### *Other postgraduate students*

Professor John Pasi **PhD** (Birmingham), consultant haematologist 1994-1999: supervised two alumni at the Royal Free, Dr Paul Fields **PhD** 1995-1998, Dr Vince Jenkins **PhD** 1995-1998

Dr Paul Giangrande **MD** 1986-1989 (now Director Haemophilia Centre United Oxford Hospitals), supervised by Dr Peter Kernoff, director 1978-1991

Dr Keith Gomez **PhD** supervised by Professor EGTuddenham Royal Postgraduate Medical School – he was also a registrar in the centre

Dr Carolyn Millar **MD** 1998-2001, (now Senior Lecture Imperial College Medical School) supervised by Dr Simon Brown, Consultant Haematologist 1999-2005

Dr May Bamber **MD** 1979-1982 – supervised by Dr Peter Kernoff and Professor Howard Thomas

Professor Christine Lee **MD** 1989 – supervisors Dr Peter Kernoff and Professor Howard Thomas, **DSc(Med)** 1996

Dr Barry Woodhams **PhD** 1983-1985, supervised by Dr Peter Kernoff

## Key clinical landmarks and research achievements 1978-2005

- 1980 Peter Kernoff appoints first computer 'expert' Mike Trott to computerize the treatment records and minimal patient demographics – the first centre in the UK to become 'computerised'
- 1981 Dr May Bamber publishes paper on non-A non-B hepatitis in collaboration with Dame Sheila Sherlock and Dr Peter Kernoff
- 1984 landmark papers published in *Nature* detailing the purification of FVIII by Ted Tuddenham's team enabling the gene to be cloned and recombinant FVIII to be produced
- 1985 paper published in *Blood* charting the first clinical use of porcine FVIII for the treatment of inhibitors
- 1982-1984 Action Research Fellowship to study non-A non-B hepatitis, Christine Lee
- 1985 paper published in *Br J Haematol* showing that 100% haemophilic patients receiving a first infusion of FVIII or FIX concentrate developed non A non B hepatitis
- 1979-1985 105 patients infected with HIV
- During this time Peter Kernoff, together with Dr Stuart Clark (now deceased and succeeded by Professor Margaret Johnson), helped set up the AIDS unit at the Royal Free. Riva Miller, the social worker and family therapist, was sent to New York for training in the new epidemic. Riva Miller later set up the same day testing clinic and AIDS counseling unit in the main hospital.
- 1985 HIV testing introduced. FVIII and FIX concentrates subjected to heat treatment.
- 1986 Ted Tuddenham left the Royal Free
- 1987 Dr Ron Hutton publishes work on snake venom – collaborative study from field work in Burma
- 1987 Peter Kernoff established UK NEQAS (this was moved to Sheffield in 1992)
- 1987 Christine Lee appointed consultant haematologist specifically to provide care and lead research for patients with HIV and hepatitis.
- 1988 First patient enrolled in European trial of *Kogenate* recombinant FVIII – Peter Kernoff was a lead investigator
- 1991 Peter Kernoff sustained disabling illness and was unable to work again and Christine Lee was appointed director
- 1991 First generation antibody testing for HCV and 1992 in house pcr test for HCV
- 1992 Prophylaxis introduced for children under the care of Dr Eleanor Goldman and later Dr John Pasi
- 1994 Dr John Pasi appointed consultant haematologist with specific responsibility for the care of children
- 1994 The Peter Kernoff building and Clive Knight Laboratories opened by the Duchess of Kent
- 1995 Dr David Perry appointed Senior Lecturer
- 1996 First child in Europe treated with recombinant FIX at RFH
- 1996 Recombinant FVIII used in children
- 1997 vCJD recognized as a risk in transfusion – adults finally treated with recombinant FVIII and FIX in 2000
- 1998 Dr John Pasi takes up post of Professor of Haematology in Leicester
- 1999 Dr Simon Brown appointed consultant haematologist with responsibility for children and a special interest in VWD
- 2000-2003 negotiations to establish a chair of haemophilia – led by Clifford Welch on behalf of KD Trust, Christine Lee as director and the then Royal Free and University College Medical School, Dean Professor Souhami.
- 2003 Dr David Perry takes up post of Consultant Haematologist in Cambridge and the post of Senior Lecturer is frozen.
- 2005 Christine Lee retires

Christine Lee February 2015