In 1951 a two year old infant Sheila Jones was diagnosed at Birmingham Children’s Hospital (BCH) with a rare condition Phenylketonuria (PKU). There was no treatment but, not accepting this, her distraught mother Mary persevered until she found help from three pioneering doctors at BCH: Dr Horst Bickel, Dr John Gerrard and Dr Evelyn Hickmans. In the hospital laboratory they worked tirelessly to prepare a special formula and Sheila was the first person in the world to receive dietary treatment for PKU.

Until now, little has been known about the life of Sheila, and her family in Birmingham, and the hardships and sacrifices they endured. It is a remarkable story of a brave little girl, her brothers, and her courageous and tenacious mother. Sheila’s contribution is immense; it led to the introduction of newborn screening and worldwide treatment for PKU. It is a great sadness that Sheila herself was unable to benefit long term but her legacy is a triumph for all those with PKU.

This is Sheila’s story until her death in Birmingham in 1999 and will be important to people with PKU, their families, health professionals and readers interested in the history of medicine.

‘This book movingly tells the story of a family and their contribution to the history of PKU’.

Professor Dame Sally Davies, Master of Trinity College Cambridge

‘A fitting tribute to a woman who paved the way to treatment for a disease and subsequently changed the lives of so many’.

Dr Fiona Reynolds, Chief Medical Officer at Birmingham Children’s Hospital

About the Author – Anne Green PhD FRCPath FRCPCH
Anne Green had a distinguished career as a Paediatric Clinical Biochemist in the UK National Health Service. She was Consultant Clinical Chemist at Birmingham Children’s Hospital from 1982-2006 and Director of the Newborn Screening/Clinical Inherited Metabolic Disorders Services for the West Midlands. She was appointed Professor of Paediatric Biochemistry at the University of Birmingham in 1994. Anne has published widely in the fields of newborn screening and inherited metabolic disorders and has held numerous posts on national and international professional organisations, including the Society for the Study of Inborn Errors of Metabolism, and the International Society for Neonatal Screening. She was co-founder of both the British Inherited Metabolic Disorders Group and the National Metabolic Biochemistry Network and was Lead Scientist for the UK National Newborn Screening Centre 2006-2011. Sheila is the fulfilment of a career-long interest in PKU.

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