

## **Proposal to Tildy's Trust**

### **Application for a Research Nurse focusing on Paediatric Drug Development in Leukaemia**

The Paediatric Drug Development Unit at the Royal Marsden is the largest unit in the UK, and one of the largest in Europe and internationally.

This request is to fund one full-time, senior Paediatric Oncology Drug Development Research Nurse to focus on leukaemia. This role will be employed by the Royal Marsden Hospital and will have daily contact directly with parents and children.

The Paediatric Drug Development Team at The Royal Marsden Hospital has an international reputation in drug development. With the ever-increasing discovery and development of novel drugs, we are now able to have more paediatric early clinical studies open and in development than ever before, thereby giving early access to new drugs to more children than has been possible in the past.

There are an increasing number of these new drugs that are becoming available for evaluation in children with leukaemia, having already shown great promise for the treatment of leukaemia in adults. A number of these drugs target the genetic events in leukaemia cells that make these cells behave malignantly. These new anti-leukaemia drugs are not used in children at the time of initial presentation as the overall cure rate for children with leukaemia is so high, and because at present those children who cannot be cured with current therapy cannot be clearly identified at diagnosis. New drugs are therefore evaluated in children whose leukaemia has come back despite initial relapse treatment and there is therefore a clear necessity to try different treatment strategies.

The evaluation of these new drugs in children with leukaemia is a highly complex process that demands intensive medical and nursing input. The Paediatric Oncology Drug Development Research Nurse is a key individual in explaining the exact nature of the studies to the families after initial discussion by the doctors. The Research Nurse is absolutely indispensable in the process of administering the new drugs and observing and documenting the side effects. The Nurse also helps to arrange investigations and collect samples to assess how well the new drugs are working. Everything has to be recorded very precisely and accurately.

#### **Job Role**

The Paediatric Oncology Drug Development Research Nurse plays a pivotal role in the successful running of clinical trials. The primary role of the Research Nurse is in implementing the clinical trial protocol so that patient safety is assured and good quality data is collected according to international clinical trial standards. The role is multifaceted, requiring the appointed individual to be an excellent communicator, educator, and manager whilst possessing a high level of practical skills in the delivery of nursing care. Such skills are crucial for effective individualised patient care which is essential for families at this stage of their disease. The importance of minimising time spent at the hospital and maximising time at home through the careful planning and management of each patient's treatment schedule cannot be overemphasized and is achieved with a dedicated, compassionate and experienced nursing team working closely with the rest of the multidisciplinary Paediatric Oncology Drug Development Team.

## **Reporting**

A report of the activities of the Paediatric Oncology Drug Development team, specifically with respect to new drug development for leukaemia and particularly with reference to the work of the Paediatric Oncology Drug Development Research Nurse will be provided to Tildy's Trust on a 6 monthly basis.

## **Costs**

The funding requested is 1 X Band 7 Research Nurse £47,474 including oncosts and is based at midpoint.