

## Introduction

CLDF has a broad range of interest in the field of paediatric hepatology. This strategy identifies the priorities for funding in CLDF's Research Funding Programme for 2015-2020 and further initiatives aimed at supporting research into paediatric Hepatology. The availability of funding will always influence CLDF's programmes.

This strategy is based upon CLDF's current and projected income levels. However, there is flexibility if the situation changes. CLDF will look to fund a PhD Fellowship and a main grants round, alternating on a two year cycle. We will also look to opportunities to work with allied organisations to joint fund the main grants round during the strategy period.

## Priorities for paediatric liver research funding 2015 - 2020

The following are identified as priority areas for research funding:-

- Biobank and bio-markers
- National Paediatric Liver Diseases Register
- National Register of long term outcome for liver transplant
- Research into primary paediatric liver disease (all conditions)
  - Prevalence/epidemiology
  - Aetiology
  - Different treatment modes
  - Outcomes
- Neonatal cholestasis
- Outcomes in adults of childhood liver diseases, including liver transplantation
- Clinical research including relevant drug trials in children and the long term effects of medication
- Social research for all ages and including adults diagnosed in childhood to include definition, measures and interventions in the following areas:-
  - Quality of life
  - Survivorship
  - Transition to adult services
  - Compliance and adherence

## Underlying principles in research delivery

In funding and delivering its research programme, the following underlying principles will be paramount:-

- CLDF gives preference to multi-centre, collaborative research
- CLDF encourages research which focuses on added value
- CLDF is keen to identify how and where its research portfolio fits into the wider research programme and agenda
- CLDF recognises that given its funding available it is more likely to fund work in the early stages of research topic continuum, particularly when it is one which is capable of being taken from bench to bedside. It will monitor its programme for up to seven years beyond the end of a project
- CLDF expects dissemination of outputs and outcomes to both lay and professional audiences

- CLDF recognises the importance of the national and international research picture including the National Institute for Health Research (NIHR) and will take note of topical issues in applying its research priorities
- CLDF will expect its Principal Investigators to know of and apply to relevant networks and schemes beyond CLDF funded research
- Research teams are expected to think 'outside the box' and are expected to consider enabling European and other collaborations

## CLDF Research Funding Mechanisms

CLDF will fund research using the following mechanisms:

- Project Grants encompassing:
  - Up to 3 years funding
  - Staff costs
  - Consumables costs
- CLDF PhD student fellowships
- Small Grants Programme ( a review of this programme will take place in 2016/17)

## Further Initiatives to support Paediatric Liver Research

CLDF will create projects during the strategy period, which increase opportunities for families and young people to learn more and be involved in research within the field. As part of this CLDF will aim to increase formal patient and public involvement in the design of research projects across the sector by creating a Research Hub, for researchers to obtain feedback from families and young people about the projects they are developing. By providing vehicles for such support CLDF could play a role in enabling a greater number of paediatric liver disease related research projects to be funded and undertaken.

## Strategy Review and Development process

This strategy has arisen out of a consultation over a period of nine months and incorporated consultation with the following stakeholders:-

- Young People
- Parents
- CLDF Scientific Committee
- Medical Professionals
- Trustees

Consultation took place via a variety of routes:-

- Surveys for medical professionals circulated via BSPHGAN and through our own networks.
- Surveys for parents and young people circulated via social media platforms and direct invitation.
- A residential consultation weekend with families and young people.
- Feedback from our National Conference's.
- One to One meetings with medical, psychology and nursing staff at Kings College Hospital, Birmingham Children's Hospital and Leeds General Infirmary.
- Discussion and ratification made at Scientific Committee and Trustee Board Meetings.