



## **BDFFA FAMILY CONFERENCE 2017**

**Crowne Plaza, Bridgefoot, Stratford upon Avon, CV37 6YR**

### **MAIN CONFERENCE PROGRAMME**

#### **Friday evening**

Welcome reception and registration from 7pm

#### **Saturday morning**

Registration

BDFFA Annual General Meeting

Science Sessions: How do we study Batten disease & Therapeutic Approaches to Batten disease

#### **Saturday afternoon**

Symptom and Care Management (not CLN3)

Education support sessions (all forms)

Personal health budgets

Paediatric resuscitation training

#### **Saturday evening**

Gala Dinner and Family Quiz

#### **Sunday morning**

Remembrance event for bereaved families

Advocacy and access to treatments

Music Therapy

Paediatric resuscitation training.

Balloon release

#### **Sunday afternoon**

Symptom and Care management (CLN3)

How families can take part in research

Genetics and carrier screening

Advanced care planning and palliative care