



Grant agreement no. 666918
PHC-14-2015 'New therapies for rare diseases'

- Research and Innovation Action -

<h2>D9.2</h2> <h3>Dissemination poster and leaflets</h3>
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WP 9 – PATIENT ORGANISATION INVOLVEMENT

Due date of deliverable: month 6

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Start date of project: 01/01/2016 Duration: 36 months

Lead beneficiary for this deliverable: Batten Disease Family Association (BDFA)

Last editor: Sara Mole

Contributors: Heather Band, Laura Codd

Dissemination Level		
PU	Public	
PP	Restricted to other programme participants (including the Commission Services)	
RE	Restricted to a group specified by the consortium (including the Commission Services)	
CO	Confidential, only for members of the consortium (including the Commission Services)	

History table

Version	Date	Released by	Comments
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1. Introduction

The preparation of a dissemination poster and leaflet is part of the tasks to be carried out within WP9 "Patient organization involvement". The WP9 leader is Heather Band (partner 14, BDFA).

1.1 General context

As part of its dissemination/communication plan, the BDFA has produced a leaflet (completed) and poster (completed and in further development) to raise awareness of BATCure among the wider public, affected families and their supporters, researchers and clinicians.

1.2 Deliverable objective

This deliverable will report on the steps followed to design the relevant leaflet and poster for the purposes of disseminating the project.

2. Summary of activities


A leaflet has been designed to provide a clear, easy to understand introduction to the BATCure project for all interested parties (see page 5). In particular, it will provide a succinct project background for affected families who are the target group for the patient/family survey to stimulate interest and provide general information about the project. The leaflet outlines the aims of BATCure, who is involved, and provides details of the BATCure website and social media pages and also includes contact information for the key project personnel.

The leaflet can be accessed on the BATCure and BDFA websites and has also been posted on the BATCure Facebook page. Followers of the BATCure Facebook page were encouraged to like and share the post containing the leaflet with the aim of reaching as wide an audience as possible.


The leaflet will also appear as a full page in the Autumn/Winter 2016 edition of the BDFA newsletter. This newsletter will be sent electronically to over 2,000 individuals and organisations on the BDFA database and also shared in print with a diverse group of NCL professionals.

The leaflet is currently being translated into 9 major European languages (Danish, Dutch, French, German, Italian, Latvian, Russian, Spanish and Swedish). The translated versions will be accessible via the BATCure and BDFA websites. Facebook and Twitter are currently being used to direct people to these websites. The details of patient groups across the EU have been collated, so that the translated leaflets can be emailed directly to local patient groups in the relevant European countries. Patient groups/contacts will be encouraged to share the leaflet with families and other interested parties.

The BATCure leaflet is as follows:



BATCure



Developing new therapies for Batten disease




Batten disease or Neuronal Ceroid Lipofuscinoses (NCL) is a life-limiting neurodegenerative disease for which there is currently no cure.

What is BATCure?

Who is involved?

BATCure is a 3-year research project funded under a European Union call (New Therapies for Rare Diseases). The goal of the project is to advance the development of new therapeutic options for patients and their families living with CLN 3, 6 or 7 Batten disease.

A consortium from seven European countries made up of ten leading scientific research groups, three companies and the Batten Disease Family Association (BDFa) who is leading part of the project and ensuring that the voice of patients and affected families is heard.

The BATCure project focuses on the most prevalent type of NCL, CLN3 (Juvenile Batten Disease or JNCL), CLN6 and CLN7 diseases.

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BATCure

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@BAT_Cure



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Developing new therapies for Batten disease

A BATCure poster has also been produced setting out the aims of BATCure, details of the consortium, work packages. This was well received when displayed at a scientific meeting by Professor Mole (namely, the III International Congress on Research of Rare and Orphan Diseases - EU Re(ACT), Barcelona, 9-12 March 2016). Most European and International scientific conferences are in English, so the poster is suitable and will be used by the whole consortium.




Developing new therapies for Batten disease



BATCure Consortium

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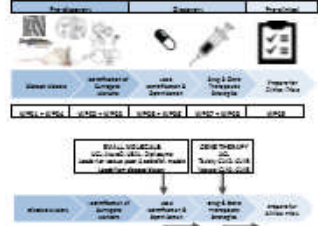




PARTNERS

CONCEPT

BATCure will investigate the natural history of Batten disease, elucidate the function of key proteins, and determine disease mechanisms, as well as develop new therapies for those forms of the disease. Batten disease is one of approximately 50 lysosomal storage disorders, in which genetic mutations disrupt the cells ability to recycle waste. Children and young adults with Batten disease suffer progressive neurological impairment, which includes cognitive, visual impairment or blindness, personality and behaviour changes, seizures, loss of motor skills, and loss of the ability to walk, talk and communicate. There is currently no treatment. This consortium brings together an leading scientific research groups, from continents and one patient organisation from across Europe, with the goal of applying their expertise and skills to Batten disease for the first time.

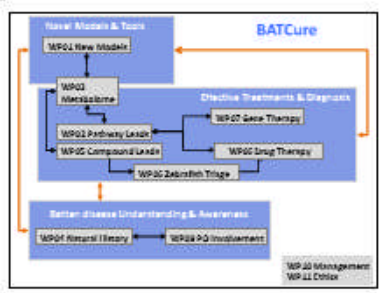




PROJECT DESIGN

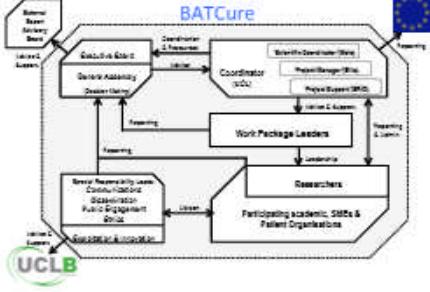
4 experimental WPs:
NEW MODELS Development, validation and optimisation of essential new models & tools
PATHWAY LEADS Identifying therapeutic target pathways using genetics & biology
MECHANISMS Identifying therapeutic target pathways and developing new genetic & molecular techniques using metabolomics
NATURAL HISTORY Natural history of the disease and beyond
COMPOUND LEADS Identifying new therapeutic compound leads
ZEBRAFISH MODEL Utilisation of zebrafish for novel drug validation
GENE THERAPY Gene therapy to the brain, eye and other organs
DRUG THERAPY Delivering new small molecule therapy to the muscle

3 facilitating or supporting WPs:
Patients' Organisation involvement
Management
Ethics

4-5 'lookalike' WPs:
30 Unpublished
50 Submitted











ORGANISATIONAL STRUCTURE



H2020-PHC-14-2015: New therapies for rare diseases
 Project: 666918
 Duration: 36 months
 Start date: 1/1/2016
 Award: €5 995 769

Web site: www.batcure.eu
 Twitter: @BAT_Cure
 Facebook: BATCure

The BDFA produced a revised version in their spring newsletter and evaluated feedback from a representative group of families who, whilst understanding the general principle found the detailed content difficult to interpret. Translation would also be costly and time consuming for wider distribution across the major European countries.

To address these issues, the BDFA are developing a further revised template. This will use more visual aids to explain the concept and work package details, allow for faster translations, and easier adaption for a wide range of uses.

3. Conclusions and future steps

The BATCure leaflet is proving effective in raising awareness of the project among a range of target audiences and the wider public, although this aspect of the work is in the early stages of development. Translated versions of the leaflet will soon be shared across the major European countries.

The current BATCure poster, is suitable and in use for scientific audiences. The BDFA, is developing the concept further. There will be the option to have a poster with a more scientific focus than the leaflet for patient, their families, related professionals (e.g. education, healthcare) and the wider public, at meetings/workshops and conferences.

The BDFA plans to display the poster at the BDFA conference, laboratory open days for families and professionals (currently taking place for the UK Consortium members, with plans to extend to all members over the course of the project) and the NCL2016 in Boston.

The revised version of the poster will be of a more general nature and thus, have the potential for much wider use. The BDFA will also provide the template for other consortium members to print the poster versions for display at meetings (including Patient Organisation events/ Laboratory open days etc.) conferences in their own countries or at relevant international events.