



BATCure Newsletter

SPRING 2017



BATTEN DISEASE FAMILY ASSOCIATION
Together we WILL make a difference

Registered Charity No. 1084908



Welcome to the first edition of the BATCure Newsletter. Our goal is to keep you informed about progress on the BATCure project and to provide some insight into the BATCure-funded research taking place at institutions across the EU.

BATCure is a 3-year research project funded by the European Union's Horizon 2020 Research and Innovation Programme. The project began in January 2016 and is progressing as planned with a great deal of research already undertaken by the project consortium. With new disease models now established, 2017 should herald further progress towards the project goal of developing the first effective treatment for patients living with Batten disease. Whilst BATCure focusses on the development of new therapies for CLN3, CLN6 and CLN7, our hope is that the research results will ultimately be of benefit to patients affected by all forms of Batten disease.

The BATCure project consortium is comprised of 14 institutions across the EU; ten leading scientific research groups, three companies and the Batten Disease Family Association (BDFA). The BDFA is leading part of the project as well as ensuring that the voice of patients and affected families is heard. In the next few months, parents/carers of affected children will be invited to share their thoughts by participating in a family survey. Further details can be found on the back cover of this newsletter.

In each edition of the BATCure Newsletter, we will shine a spotlight on some of the institutions involved in BATCure and the individuals who work there, exploring their roles in the project.

Spotlight on...

Professor Sara Mole, University College London

Sara E Mole is Professor in Molecular Cell Biology at UCL. She is a recognized world leader in Batten disease with over 20 years' experience, with particular expertise in genetics. Professor Mole acts as the overall Coordinator for BATCure and chairs the General Assembly and Executive Board. The Mole laboratory will also contribute to several areas of research as part of the BATCure project.



"I act as coordinator of BATCure, ensuring that it proceeds as planned to achieve its aims of understanding more about Batten disease and particularly developing new therapies for CLN3, CLN6 and CLN7 diseases. Towards this, I host regular meetings with all partners to share and discuss progress. I also direct the work of my own lab within UCL that contributes to specific work packages."

Spotlight on...

Cristina Soriano Carpena, University College London

Cristina is the European Project Manager at the UCL European Research and Innovation office where she is responsible for monitoring and supporting the work of institutions who are part of BATCure. She is in charge of the financial, contractual and administrative matters directly associated with the project. In collaboration with the Project Coordinator, she monitors project progress against the plan and liaises with the dedicated EU Project Officer in Brussels.



Cristina will be leaving UCL in April to return to her native Spain and we would like to take this opportunity to thank her for all her work on BATCure. The consortium team has very much enjoyed working with her and the support she has provided has been invaluable in keeping the project on track.

To find out more about **BATCure**

www.batcure.eu



BATCure



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Spotlight on...

Professor Juan P. Bolanos' Group, La Universidad De Salamanca (USAL)

Cell metabolism or a cell's daily operations to maintain a healthy life are accomplished through many complex reactions. In many diseases, such as Batten disease, this process can be disrupted or "re-wired". USAL's contribution to BATCure focuses on finding out whether this problem occurs in key brain cells (neurons and/or astrocytes) and if this is contributing to, or causing, cell death.



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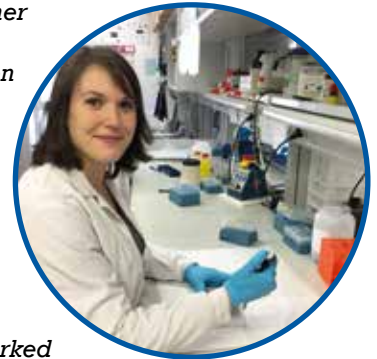
"I am the BATCure Work Package 2 Coordinator and am responsible for the work to understand energy pathways in neurons and astrocytes of the CLN3, CLN6 and CLN7 mice models of the disease. We have found compelling evidence indicating there is an important re-wire going on in these cells.



We are currently committed to identifying the possible molecular target(s) in the Batten disease models to look for potential therapeutic targets. For BATCure 2017, we will study the mitochondria (powerhouse of the cell) and a specific chain of events that are affecting the brain cells during the progression of the disease."

Professor Juan P. Bolanos
Research Leader, USAL

"I am a Postdoctoral Researcher in Professor Bolaños' group devoted to the characterization of brain energy metabolism in the CLN3, CLN6 and CLN7 mice models of Batten disease.



I finished my PhD in Biotechnology at the University of Salamanca in September 2015, and then worked at the Mitochondrial Biology Unit at MRC in Cambridge, UK.

I have a strong background in the study of mitochondrial metabolism and its role in how brain cells manage their energy supply."

Irene Lopez-Fabuel
Postdoctoral Researcher, USAL



BATCure has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 666918



BATCure Family Survey 2017

What is the BATCure Family Survey and who is it for?

The BATCure family survey is a short questionnaire for parents/carers of children affected by all forms of Batten disease.

It is an opportunity for the voice of families to be heard in the BATCure research.

The survey is designed to explore the perspective of families, gathering your thoughts about research and clinical trials in order to inform and help prepare for any future treatments developed as part of the BATCure project.

How can I get involved?

The survey will be launched in Spring/Summer 2017 with further details sent to all BDFa members. It will also be advertised on the BDFa website and social media sites.

It will be a secure, anonymised online survey taking around 15 minutes to complete per affected child.

It is really important that as many families as possible participate and we hope that you will be able to take part.

BDFa Survey Contact

Laura Codd
BATCure Administrator - BDFa
lauracodd@bdfa-uk.org.uk
www.bdfa-uk.org.uk