BIOGRAPHICAL SKETCH

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NAME: Dr Lyndsey (Craven) Butterworth

eRA COMMONS USER NAME (credential, e.g., agency login):

POSITION TITLE: Engagement & Communications Lead, Wellcome Centre for Mitochondrial Research, Newcastle University

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Start Date	Completion Date	FIELD OF STUDY
Newcastle University, UK	PhD	09/2005	02/2010	Mitochondrial Studies in Oocytes & Embryos
University of Glasgow, UK	MRes	09/2000	06/2001	Biomedical & Life Sciences
University of Newcastle upon Tyne, UK	BSc (Hons)	09/1997	06/2000	Biomedical Science (Genetics)

A. Personal Statement

I have worked within the Wellcome Centre for Mitochondrial Research at Newcastle University for over 20 years as a member of the multidisciplinary team comprised of clinicians, healthcare professionals, scientists and researchers all committed to transforming the lives of those affected by mitochondrial disease and dysfunction. I began as a Research Assistant within the Centre in 2003 before completing my PhD in 2010 and taking on a post-doctoral position within the team. More recently, my role has changed and I now lead on the development and delivery of our engagement and communication strategy across the Centre to ensure our research priorities continue to be patient-focused and that our science communication is accessible to all.

My previous research area and PhD project involved developing and assessing the novel IVF-based technique known as mitochondrial donation, a reproductive option that can prevent transmission of mitochondrial DNA disease from mother to child. I led on the early optimisation of this technique following a successful appeal to the Human Fertilisation and Embryology Authority (HFEA) that allowed the use of abnormally fertilised human embryos for the first time as part of the preclinical research study. This contribution led to my recognition as first author in a scientific paper published in the journal *Nature*. I was also responsible for assessing the safety of the technique in terms of its potential to prevent transmission of mitochondrial DNA disease, data that was crucial for an independent scientific review on the efficacy of mitochondrial donation which led to HFEA approval for use of the technique in the UK.

A significant part of my research project involved engaging and communicating the science behind mitochondrial donation with different audiences as part of the law change required in the UK to allow access to those who could benefit. This highlighted the importance of effective communication and engagement, which I consider to be a crucial aspect of all scientific research and something I feel very passionate about. My current role involves using the results of our innovative engagement research to raise awareness of mitochondrial disease and dysfunction with citizens and policy makers for the benefit of the entire mitochondrial community. To date, this approach has involved working collaboratively with the global mitochondrial community to engage new audiences and increase the profile of mitochondrial disease. This has been hugely impactful and has increased the reach of our key messages across the world, as summarised here. I believe this experience and the skills I have gained will be of huge benefit to E-Mit in terms of communicating with members and the wider public about the importance of mitochondrial research, whilst also raising the profile and extending the reach of the society.

B. Positions, Scientific Appointments and Honors

Feb 2023	PPIE Co-lead for the Newcastle BRC Neuromuscular, Rare Disease & Mitochondrial Dysfunction Theme
Feb 2023	Lead on the organisation & delivery of multiple engagement events for Rare Disease Day 2023
Nov 2022	Co-lead on the organisation & delivery of a UK Parliamentary drop in event provided by the WCMR
Oct 2022	Lead on a 'Twitter Takeover' with global patient organisations during World Mitochondrial Disease Week
Feb 2022	Co-developed a film on mitochondrial disease & led on dissemination for Rare Disease Day 2022
Nov 2021	Coordinated a review & update of the WCMR website (https://www.newcastle-mitochondria.com/)
June 2021	Joined the IMP Scientific Committee (https://www.mitopatients.org/research/scientific-committee)
Jan 2021	Co-lead on development & delivery of engagement & communication for Project PEARL
June 2020	Nominated as Communication Co-lead for the Mitochondria & Neuromuscular Theme, NUTCRI
Jan 2020	Steering group member for the Mitochondrial Disease Priority Settings Partnership (PSP)
May 2019	Presented at the International Mito Patient Annual General Meeting (representing The Lily Foundation)
March 2018	Contributed to the NCCPE 'What Works' guide for engaging the public through social media
Jan 2018	Responsible for management & delivery of WCMR social media content across platforms (@mitoresearch)
May 2017	Joined The Lily Foundation team in a science communication role (part time)
Feb 2017	Invited speaker: Policy Academy: Research to Policy Journey, Newcastle University
March 2016	Guardian University Award 2016: Research Impact
July 2016	Selected for a Public Engagement Masterclass, Wellcome Genome Campus, Cambridge
Dec 2016	Selected for Royal Society MP Pairing Scheme, Houses of Parliament, London
March 2015	Selected for poster presentation: SET for BRITAIN, Houses of Parliament, London

C. Contributions to Science

Rhys H Thomas, Amy Hunter, **Lyndsey Butterworth**, Catherine Feeney *et al*. Research priorities for mitochondrial disorders: Current landscape and patient and professional views. *J Inherit Metab Dis*. 2022 Jul;45(4):796-803. doi: 10.1002/jimd.12521.

Craven L, Murphy JL, Turnbull DM. Mitochondrial donation - hope for families with mitochondrial DNA disease. *Emerg Top Life Sci.* 2020 Sep 8;4(2):151-154. doi: 10.1042/ETLS20190196.

Craven L, Murphy J, Turnbull DM, Taylor RW, Gorman GS McFarland R. Scientific and Ethical Issues in Mitochondrial Donation. *The New Bioethics*. 2018 Apr;24(1):57-73. doi: 10.1080/20502877.2018.1440725.

Craven L*, Tang MX*, Gorman GS, De Sutter P, Heindryckx B. Novel reproductive technologies to prevent mitochondrial disease. *Hum Reprod Update*. 2017 23:1-19. doi: 10.1093/humupd/dmx018. (*joint authorship)

Craven L, Alston CL, Taylor RW, Turnbull DM. Recent Advances in Mitochondrial Disease. *Annu Rev Genomics Hum Genet*. 2017 Aug 31;18:257-275. doi: 10.1146/annurev-genom-091416-035426.

Hyslop LA, Blakeley P, **Craven L**, et al. Towards clinical application of pronuclear transfer to prevent mitochondrial DNA disease. *Nature.* 2016 16;534 (7607):383-6. doi: 10.1038/nature18303.

Craven L, Herbert M, Murdoch A, Murphy J, Lawford Davies J, Turnbull DM. Research into Policy: A Brief History of Mitochondrial Donation. *Stem Cells*. 2016 Feb;34(2):265-7. doi: 10.1002/stem.2221.

Chinnery PF, **Craven L**, Mitalipov S, Stewart JB, Herbert M, Turnbull DM. The challenges of mitochondrial replacement. PLoS Genet. 2014 Apr 24;10(4):e1004315. doi: 10.1371/journal.pgen.1004315.

Craven L, Tuppen HA, Greggains GD, Harbottle SJ, Murphy JL, Cree LM, Murdoch AP, Chinnery PF, Taylor RW, Lightowlers RN, Herbert M, Turnbull DM. Pronuclear transfer in human embryos to prevent transmission of mitochondrial DNA disease. *Nature*. 2010 6;465 (7294):82-5. doi: 10.1038/nature08958.