

MitoSoc Symposium:

The sociology of mitochondrial disorders and novel reproductive technologies

Friday 5th May 2017, London

Organisers: Dr Cathy Herbrand, Dr Rebecca Dimond
Supported by the **BSA Human Reproduction Study Group**and the **Foundation for the Sociology of Health and Illness**

In February 2015 the UK became the first country to legalise high-profile and controversial mitochondrial donation techniques, which aim to prevent the transmission of inherited disorders by creating offspring using genetic material from three individuals. During the years preceding this legalisation, the debates were largely dominated by ethical issues and safety concerns. Little reference was made to empirical data in relation to affected families and the contribution from social science was limited.

This left unspoken the social, cultural and economic context within which the mitochondrial debates played out, and the complexities of living with mitochondrial disorders, including making sense of diagnosis, family communication and reproductive choices.

This event will be the first to bring together scholars interested in developing sociological thinking around mitochondrial donation. It will also contribute to an interdisciplinary dialogue on the implications of these technologies for policy in the field.

Conference Details

The conference will take place at the <u>BSA Room</u>, Imperial Wharf, Fulham, London SW6 2PY.

Register online at:

http://store.dmu.ac.uk/product-catalogue/faculty-of-health-life-sciences/misc/mitosoc-symposiumthe-sociology-of-mitochondrial-disorders-and-novel-reproductive-technologies

Registration Fees (incl. lunch and refreshments): £20

Several bursaries are available to post-graduate students on a first-come, first- served basis. For more information, please contact: cathy.herbrand@dmu.ac.uk



Programme: MitoSoc Symposium 5th May 2017

| 10:00-10:15 | Welcome and Registration |
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| 10:15-10:30 | Introduction |
| 10:30-12:00 | Missing voices and absent perspectives in the mitochondrial donation debates |
| | Discussant: Rosamund Scott |
| | Neil Stephens : 'Contested politics and mitochondrial donation: boundary work, campaigning and identity when bioethics goes to parliament' |
| | Cathy Herbrand: 'Mitochondrial donation: Who are the potential beneficiaries?' |
| | Erica Haimes : 'Rendering the invisible visible: the roles, values and interests of egg providers in mitochondrial research and therapy' |
| 12:00-13:00 | Lunch |
| 13:00-14:30 | The complexities of living with mitochondrial disorders |
| | Discussant: Joanna Poulton |
| | Lydia Harper : 'Living with Leber hereditary optic neuropathy: Negotiating stigma in everyday life'. |
| | Julia Tonge: 'The implications of clinical relationships in making reproductive decisions' |
| | Rebecca Dimond : 'Believing in hope: the patients' perspectives on mitochondrial disorders' |
| 14:30-15:00 | Coffee break |
| 15:00-16:00 | Mitochondrial donation in different contexts |
| | Discussant: Ilke Turkmendag |
| | Jacqueline Luce: 'Participatory knowledge politics of governing mitochondrial replacement techniques' |
| | Sandra Gonzalez-Santos: 'Made in Mexico? Reports of the "world's first' mito baby"' |
| | Ken Taylor : 'Sharpening the cutting edge: additional considerations for the UK debates on embryonic interventions for mitochondrial diseases' |
| 16:15-17:00 | Panel discussion: 'Integrating a sociological approach into the interdisciplinary dialogue on mitochondrial donation' |
| | Discussants: TBC |

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