

15 September 2017

Dear Patient and families

CMT Patient information day – Saturday 30 September 2017 from 10.00- 14.00

Thank you for registering for the forthcoming patient day which is being organised by the MRC Centre for Neuromuscular Diseases, Institute of Neurology, University College London in association with Charcot Marie Tooth UK.

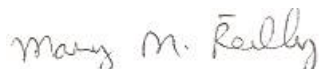
The event will be held in the Clinical Neuroscience Lecture Theatre based on the lower ground at 33 Queen Square, WC1N 3BG starting with registration at 10.00am (please note that the lecture theatre is not situated inside the National Hospital for Neurology and Neurosurgery). The entrance to the lecture theatre is on the same side of the square as the main Hospital Entrance, but further along the road. The lecture theatre is on the Lower Ground floor but there is a lift. The lecture theatre itself is stepped (but shallow steps), and there are a couple of spaces at the top of the lecture theatre for wheelchairs.

Attached to this letter are the speaker biographies and location maps.

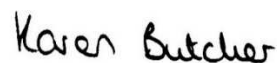
We have over 100 delegate registrations however if you have registered and then are unable to attend we would ask that you deregister your place via Eventbrite <https://patient-info-day-2017.eventbrite.co.uk> to free up that place for another attendee or email (Jacky Bauer- event organiser) [j.bauer@ucl.ac.uk](mailto:j.bauer@ucl.ac.uk) and [enquiries@cmt.org](mailto:enquiries@cmt.org) or call 0203 448 8111 or if you have any changes to your booking.

The event will include a light sandwich lunch (meat and vegetarian) with refreshments – unfortunately we will be unable to cater for other dietary requirements.

Yours sincerely



Professor Mary Reilly MD, FRCP, FRCPI  
Professor of Clinical Neurology  
and Consultant Neurologist  
Head of Division of Clinical Neurology



Karen Butcher  
Chief Operating Officer  
CMTUK  
[enquiries@cmt.org](mailto:enquiries@cmt.org)

01202 474203

MRC

Centre for  
Neuromuscular Diseases



## Charcot-Marie-Tooth disease patient day

Saturday 30 September 2017

Lecture Theatre, Lower Ground, 33 Queen Square, National  
Hospital for Neurology and Neurosurgery, Queen Square, London

WC1N 3BG

*Hosted by the MRC Centre for Neuromuscular Diseases*

### PROGRAMME

10.00 – 10.15	Registration
10.15 – 10.30	Introduction Karen Butcher Charcot-Marie-Tooth UK
10.30 – 11.00	Introduction to CMT Professor Mary Reilly MRC Centre for Neuromuscular Diseases
11.00 – 11.30	Management of CMT Dr Matilde Laurá MRC Centre for Neuromuscular Diseases
11.30 – 12.00	Therapy in CMT Dr Gita Ramdharry MRC Centre for Neuromuscular Diseases
12.00 – 12.45	LUNCH – foyer of lecture theatre and seating in 33QS outpatients area
12.45 – 13.15	Nursing in CMT Karen Bull MRC Centre for Neuromuscular Diseases
13.10 – 13.45	Employment – issues for people with disabilities Catherine West, MP for Hornsey and Wood Green
13.45	CLOSE

## Speaker biographies

### Professor Mary Reilly – Professor of Neurology and Consultant Neurologist



Professor Mary M. Reilly studied medicine at University College Dublin. After doing two years of Neurology in Dublin, she did her MD thesis on Familial Amyloid Polyneuropathy in the Institute of Neurology, Queen Square, London. She then completed her Clinical Neurological training subspecialising in peripheral nerve diseases at the National Hospital for Neurology and Neurosurgery, the Royal Free Hospital and Guy's Hospital. Since 1998, she has been a Consultant Neurologist and since 2010 a Professor of Neurology at the National Hospital for Neurology and Neurosurgery with a clinical and research interest in inherited peripheral nerve disorders, especially CMT. She is currently President of the Association of British Neurologists and immediate past President of the International Peripheral Nerve Society.

### Dr Matilde Laurá – Consultant neurologist



Dr Matilde Laurá studied medicine and completed her specialist training in Neurology at the University of Messina, Italy. She obtained a PhD in Neuromuscular Diseases in 2003 and from 2006 started working as clinical research fellow under Professor Reilly at the Institute of Neurology, UCL. Since 2013 she has been a Consultant Neurologist in the peripheral nerve team at the MRC Centre for Neuromuscular diseases with a clinical and research interest in inherited peripheral neuropathies, especially CMT.

### Dr Gita Ramdharry - Physiotherapist Associate Professor



Dr Gita Ramdharry completed a BSc in Physiotherapy at the University of East London in 1995, after which she worked as a clinical physiotherapist in various London teaching hospitals, specialising in neurology in 1997. She completed an MSc in Physiotherapy at the University of Brighton in 2004 and went on to pursue a PhD in Neurological Studies at University College London that same year. She completed her thesis entitled “Compensatory Strategies While Walking in People with Charcot - Marie - Tooth Disease: Impact and Intervention” in 2008. She is one of the professional advisors to the CMTUK patient support group, speaking regularly at conferences and meetings. Gita continues to conduct trials of rehabilitation for people with CMT. She has recently completed an study of aerobic exercise training and is currently supervising a home based study of strength and balance training for people with CMT, funded by CMTUK.

## **Karen Bull – Clinical Nurse specialist**



Karen Bull joined the Centre for Neuromuscular Diseases as a Clinical Nurse Specialist for neuromuscular disorders in 2006. In this time she has developed a specialist interest in the care of the peripheral nerve patients, offering support education and monitoring of the client group. Prior to joining the team she had a varied career which included general medical and paediatric experience spending 14 years in general neurology, the last six of which were spent as the ward manager for neuro-medical patients and stroke rehabilitation. Karen has now retired from her full time post with the peripheral nerve team after 10 years of service playing a pivotal role in the care of so many patients with CMT. Her replacement, who started recently is Mr Albert Onde, see biography and photograph below.



## **Albert Onde Clinical Nurse Specialist**

Albert Onde has worked at the National Hospital for Neurology and Neurology since 2015 on the Day Care Unit where he developed interest in rare neurological disorders. He became a Clinical Nurse Specialist in Multiple Sclerosis in 2016 with an interest in disease-modifying treatments particularly the Alemtuzumab service. He has also worked on the Acute Medical Unit at the University College Hospital and various ward-based nursing roles at Blackpool Victoria Hospital. He joined the MRC Centre as a clinical nurse specialist in neuromuscular disorders and replaces Karen Bull.



## **Karen Butcher – Charcot Marie Tooth Disease UK**

Karen Butcher is the Chief Operating Officer/Fundraising Manager of Charcot-Marie-Tooth UK, the UK's national support organisation for people with CMT. She has been involved with the charity since 1990, and has gained much knowledge of CMT from attending many patient and professional conferences. She also has CMT Type 1a, as does both her children and her mother, enabling her to give a personal perspective when helping newly diagnosed people.



## **Catherine West – MP for Hornsey and Wood Green**

Catherine West is the Labour Member of Parliament for Hornsey & Wood Green. Before becoming an MP she was Leader of Islington Council, Chair of London Councils' Transport & Environment Committee and a member of the LGA Finance Panel. In 2013 she was awarded the 'Local Authority Leader of the Year' award by the Local Government Information Unit for her work leading the Islington Fairness Commission. Catherine speaks five languages and holds a degree in Social Science and Languages and a Masters Degree in Chinese Studies from the School of Oriental and African Studies. She was a Shadow Foreign Office Minister from 2015-17 and is a member of the International Trade Committee in Parliament.



**CMT PATIENT DAY**  
**33 QUEEN SQUARE, LONDON WC1N 3BG**

**INFORMATION PACK**

**INCLUDES:**

- Wi-Fi
- Meeting location
- How to get to Queen Square
- Taxi numbers

Wi-Fi is available - Please note that the signal in the lower ground floor is not very good and you may need to go up to the ground floor to make calls etc. If you require Wi-Fi access:

- log into your device as UCLguest, click on the Event code link
- add event code [CMT2017](#) to create your own account. Eduroam is also available for University staff.

**Location**

The patient day is being held in the Lecture theatre at 33 Queen Square which is next door to the National Hospital for Neurology and Neurosurgery. See map links below and at the end of this information pack for directions and maps.

<https://www.ucl.ac.uk/ion/Queen-Square-Map.pdf>

<https://www.uclh.nhs.uk/OurServices/OurHospitals/NHNN/Pages/Home.aspx>

33 Queen Square is on the same side of the National Hospital (red brick building). If you pass the hospital on the left and keep going you will come to 33 QS. Go through the main door and go down the staircase in front of you.

The lecture theatre is situated on the lower ground of 33 Queen Square. Go through the swing doors, through the outpatients department and down the stairs. There are lifts available, if you require a lift, from outpatients head for the door in the left corner, then turn right until you reach the lift, turn right when you leave the lift and then right again.

Please note the lecture theatre can be cold so please bring layers!

Lunch will be served in the foyer of the lecture theatre, please note there is no seating in this area however we have booked the 33 outpatients area upstairs which does have seating (albeit limited).

## How to get to Queen Square

### By Tube/Bus:

The nearest station to Queen Square is Russell Square (Piccadilly Line), Holborn (Piccadilly and Central Lines) station is only a ten minute walk. Tube/Bus journey planners and times can be found [here](#). A London Underground map can be found here: <http://www.tfl.gov.uk/assets/downloads/standard-tube-map.gif>

### By Car:

There is limited car-parking in Queen Square which requires 'Pay & Display' (Mon-Fri 08:30-18:30 & Sat 08:30-11:30). There is an [NCP car park](#) near the Brunswick Centre.

### By Rail:

Queen Square is approximately half a mile south of St. Pancras, Kings Cross and Euston Stations. From Kings Cross, Russell Square underground is one stop on the Piccadilly Line. Euston Station is a short walk down Woburn Place. Times and fares are available from [here](#).

### By Air:

[London Heathrow](#) is on the Piccadilly Line, journey time on the tube is just over one hour to Russell Square.

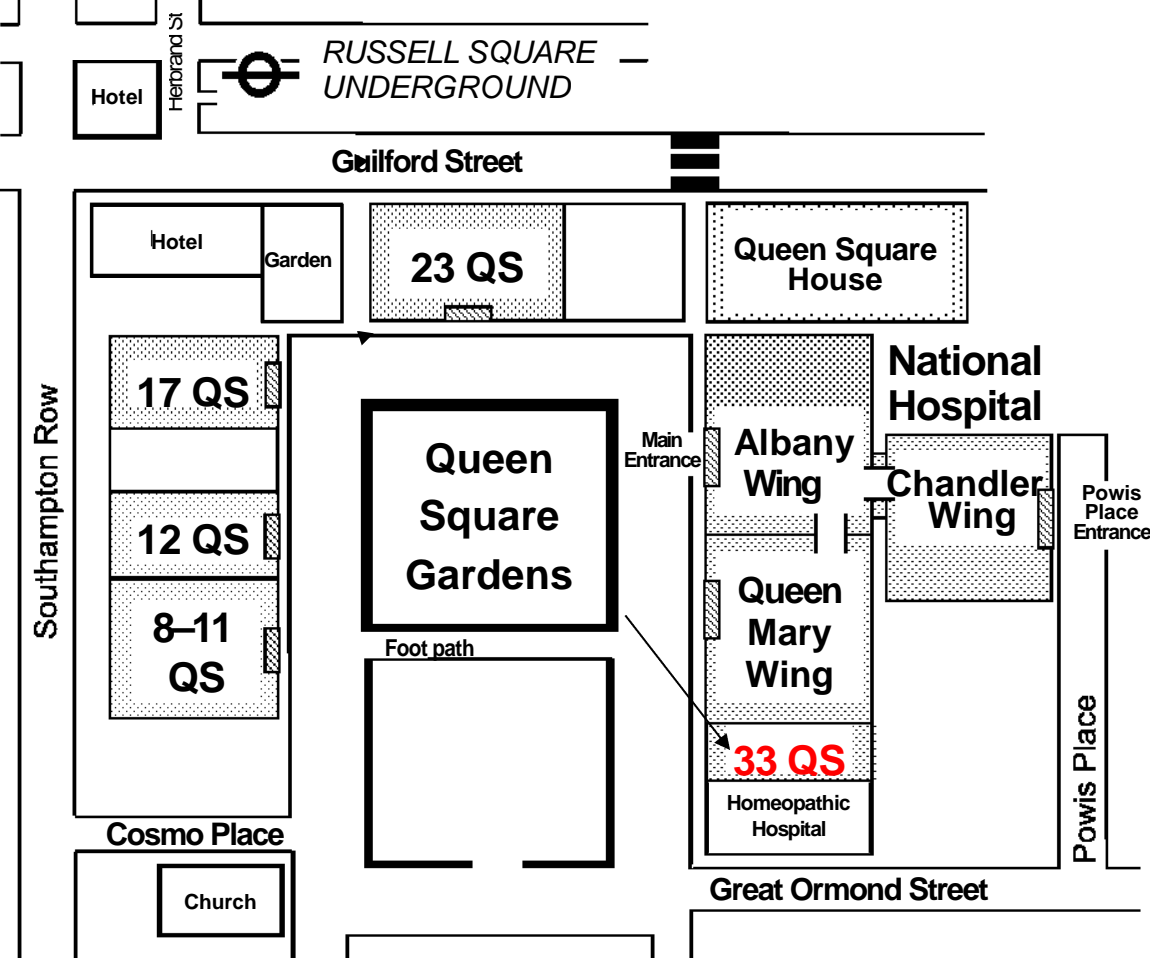
Heathrow Express is only 15 minutes ( this is a more expensive and indirect route to the venue)  
[https://www.heathrowexpress.com/?tid=WEXT12191&CMP=PSB023&utm\\_source=google&utm\\_medium=cpc&utm\\_campaign=EMEA\\_UK\\_EN\\_GENERIC\\_SEARCH&utm\\_term=heathrow%20to%20paddington&gclid=C13F1YC9v9MCFcUp0wodf-UMQQ](https://www.heathrowexpress.com/?tid=WEXT12191&CMP=PSB023&utm_source=google&utm_medium=cpc&utm_campaign=EMEA_UK_EN_GENERIC_SEARCH&utm_term=heathrow%20to%20paddington&gclid=C13F1YC9v9MCFcUp0wodf-UMQQ)

[Gatwick Airport](#) has a fast link with London Victoria Station, journey time 30-35 mins and [London Stansted](#) has a fast connection to London Liverpool Street Station, journey time 45 mins.

### Taxi number

Radio Cars 020 7383 3333 – you will be asked for your name and location – the location is 33 Queen Square, London WC1N 3BG

# Queen Square Buildings





## How to get to Queen Square

Arriving by national rail:

Buses leave from the following mainline train stations to Russell Square:

Euston – 68, 168, 59, 91

King's Cross – 59, 91

Waterloo – 59, 168, 188

Charing Cross – 91

Paddington - 7

Arriving by car:

Parking is available at the NCP Brunswick Square car park on Marchmont Street, London WC1N 1AF, which is a five minute walk to Guildford Street. The cost is £15.50 for 24 hours.

<http://www.ncp.co.uk/find-a-car-park.htm>

Arriving by tube:

The nearest tube stations are Russell Square, Euston and King's Cross.

