Huntington’s Disease Service

Newsletter

April 2015

This newsletter is sent twice yearly to keep you up to date with events in the Leicestershire HD Service. If you no longer wish to receive this or know someone who wants to be included on our mailing list, please contact Caroline Hallam, our secretary on:

Tel: 01509 561615
Fax: 01509 561646

WELCOME TO:

Dr Reza Kiani, Consultant Psychiatrist

Dr Reza Kiani is a Consultant with specialist interest in neuropsychiatry of Huntington’s disease, epilepsy, dementia, autism and intellectual disability. He is currently an enhanced appraiser and a core educational/college tutor for Leicestershire Partnership NHS Trust and a clinical teacher working with the medical school of the University of Leicester. He has been working in Leicester since 2005.

MEMBERS OF THE HUNTINGTON’S DISEASE COMMUNITY TEAM ARE:

- Dawn Freire-Patino  HD Community Matron
- Jackie Clapton  HD Community Nurse
- Janet Grant  HD Community Nurse
- Dr Reza Kiani  Consultant Psychiatrist
- Dr Maria Dale  Clinical Psychologist
- Nicky Calow  Senior Dietitian
- Kerry Sanderson  Speech & Language Therapist
- Rachel Clarke  Occupational Therapist
- Siobhan Dandolo  Physiotherapist
- Amy Kent  Physiotherapist
**REFERRALS TO THE SERVICE:**

For people living in Leicestershire, family members can refer themselves to the Service by ringing our HD Community Matron, Dawn Patino on 01509 561615.

For people outside of Leicestershire, your GP can refer you by:

1. Ringing Caroline, our Secretary on 01509 561615.
2. Caroline will send your GP or Consultant a Referral Form.
3. Once completed, your local health body needs to agree funding.
4. We then organise contact at a venue and time to suit you.

If you have family members outside of Leicester, please let them know this information.

---

**OUTPATIENTS CLINICS, LEICESTER:**

Our monthly outpatient’s clinic held at the Bradgate Unit, Glenfield Hospital will now be held on the 2nd Thursday of every month.

---

**WE SAY GOODBYE TO.......**

**DR JULIA MIDDLETON**

ASSOCIATE SPECIALIST IN PSYCHIATRY

Dawn Freire-Patino, Leicestershire HD Community Matron, along with Dr Reza Kiani, Consultant Psychiatrist continues with the HD Advisory Service in Northampton for people with HD in their own homes.

---

**RELOCATION OF MILL LODGE HUNTINGTON’S DISEASE INPATIENT UNIT:**

LPT is proposing to move its specialist Huntington’s Disease inpatient and community services from their current base, at Mill Lodge, Kegworth, to a new purpose-built facility on the site of Stewart House, where we currently provide mental health rehabilitation inpatient care for adults with complex mental health needs. Further information can be found here: [http://www.leicspart.nhs.uk/_InvolvingYou-Engagement-HuntingtonsDiseaseservicerelocation.aspx](http://www.leicspart.nhs.uk/_InvolvingYou-Engagement-HuntingtonsDiseaseservicerelocation.aspx)

---

**FRIENDS AND FAMILY TEST:**

Between December 2014 and March 2015 we have received the following feedback:

17 of you returned your Friends and Family Test cards.

16 of you would be extremely likely to recommend our Service.

1 of you would be likely to recommend our Service.

**Comment:**

All the people we have had contact with since HD diagnosis have been absolutely wonderful. Very caring and giving us plenty of information. We feel a lot of trust in our Community Nurse who we see most of the time.
<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Venue</th>
<th>SPEAKERS</th>
<th>Date</th>
<th>Time</th>
<th>Venue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friday 20 March 2015</td>
<td>1.00pm – 3.00pm</td>
<td>Mansion House Glenfrith Glenfield Hospital Site Groby Road Leicester LE3 9QF</td>
<td>Terri Askin and Annie O’Conner from the Assistive Technology Team</td>
<td>Friday 11 September 2015</td>
<td>1.00pm – 3.00pm</td>
<td>Mansion House Glenfrith Glenfield Hospital Site Groby Road Leicester LE3 9QF</td>
</tr>
<tr>
<td>Tuesday 9 June 2015</td>
<td>6.30pm – 8.30pm</td>
<td>The Mett Centre Lee Street Lee Circle Leicester LE1 3RF</td>
<td></td>
<td>Tuesday 1 December 2015</td>
<td>6.30pm – 8.30pm</td>
<td>To be arranged</td>
</tr>
</tbody>
</table>

**SPEECH AND LANGUAGE THERAPY:**

LPT’s METT Centre (is a day care facility which supports and promotes the independence of clients who have a Huntington’s disease diagnosis so that they can access and utilise the Mett Centre activity programme safely).

The METT Centre is continuing to offer an excellent speech and language therapy group to their clients with HD. In collaboration with the local therapist they have developed a fun ‘Expressions’ group that has met regularly for the last twi years to practise communication skills.

They complete exercises together that might look like pulling funny faces at one another, but can actually help improve the strength and movement of the muscles used for speech. These include exercises for lip, cheek and tongue strength and breathing exercises to prevent people from running out of air when they talk.

The team has written tongue twisters, limericks and developed games to ensure it stays interesting, including blow football which can get surprisingly competitive!

The group is regularly assessed with outcome measures to ensure that clients continue to benefit and enjoy the group. The team have reported group members now have better clarity of speech, increased control of saliva and are able to chat for longer. If you would like to discuss exercises that may help with your or your relative/client’s speech or breathing please contact speech and language therapist Kerry Sanderson on 0116 295 4692.

*Kerry Sanderson*
*Speech and Language Therapist*
In addition to collecting data for the large studies REGISTRY and ENROLL-HD, the LPT HD Service has been increasingly involved in undertaking research and publishing findings in scientific peer-reviewed journals.

A paper describing a group that was undertaken for carers of people with HD, was published in 2014 and is the first article to appear in a scientific journal that focused on a psychoeducational intervention designed specifically for carers of HD patients. Thanks to everyone who took part in the group. Let us hope that this draws attention to the benefits that HD carer support can have.

Collaborations with the Leicester University School of Psychology have examined the psychological impact of predictive genetic testing. This study involved systematically reviewing the research published in this area. The paper concluded that the psychological impact of predictive genetic testing was not found to be associated with test result. No detrimental effect of predictive genetic testing on non-carriers was found, although the process was not found to be psychologically neutral. Fluctuation in levels of distress was found over time for carriers and non-carriers alike.

The LPT HD Service presented three posters in Barcelona (September 2014) for the 8th Plenary meeting for the European HD Network. These looked at gender differences in anxiety and depression among HD expansion carriers, the patterns of anxiety and depression across disease-stage (including those who are not motor symptomatic) and a study looking at HD partner carer experiences. The abstracts of these three studies were published and the full papers are currently being written.

A review of anxiety in HD undertaken by Dr Maria Dale (Clinical Psychologist) and Dr Erik van Duijn in Netherlands, was also accepted for publication in an international journal. Although anxiety is a common complaint in HD, it remains an under-researched area.

Other studies that our HD service are currently involved in include a study of over 1,000 participants, using REGISTRY data, examining the prevalence and predictors of pain in HD; a study examining the validity of the Hospital Anxiety and Depression Scale (HADS) in HD, and a project looking at the use of the Care Programme Approach in HD. Finally, in conjunction with researchers across numerous countries, we are involved in an international survey and review of psychological interventions for HD.

If anyone would like more information on any of these projects, or would like to discuss research in HD, please do not hesitate to contact us on 01509 561615.

“We would also like to hear from anyone affected by HD who would like to be involved in the design of future research projects. If you are interested, or would like to find out more information, then please contact Maria Dale on 0116 295 3098”.

References

Dr Maria Dale
Clinical Psychologist
USEFUL WEBSITES:

**HUNTINGTON’S DISEASE ASSOCIATION:**
The Huntington's Disease Association (HDA) is a UK registered charity which supports people affected by Huntington's disease (HD). It is a voluntary organisation that provides information and advice to families and friends.

**Web site:** www.hda.org.uk

**HD BUZZ:**
HD Buzz is a website written by Scientists describing research in HD. It is written in plain English in a way that is easy to understand.

**Web site:** www.hdbuzz.net

**WHAT IS THE HDYO?**
The Huntington's Disease Youth Organisation is a non-profit voluntary organisation that provides appropriate information and education, along with support for young people impacted by Huntington's disease.

**Web site:** www.hdyo.org

---

Enroll-HD will be the world's largest observational study for Huntington’s Disease families.

The sponsor of this research is the CHDI Foundation, a privately-funded, not-for-profit biomedical research organization devoted to a single disease – Huntington’s Disease. Their mission is to develop drugs that will slow the progression of Huntington’s Disease and provide meaningful clinical benefit to patients as quickly as possible.

It is a resource for the entire HD community, including patients, families, patient advocates, clinicians and other healthcare professionals, researchers, and anyone else who has a connection to HD. The study is designed to be a clinical research platform that will enable healthcare professionals, scientists, and families affected by HD to work together towards an improved understanding of HD and better care and new effective treatments for HD patients.

The study builds on and unites two successful studies: COHORT in North America and Australia, and REGISTRY in Europe. Enroll-HD is also adding new participants from Latin America and New Zealand, and possibly additional regions in the future. The first participant joined Enroll-HD on 26 July 2012 at the University of Tennessee Health Science Center in the United States.

For more information on how you can participate please go to: **Web site:** www.enroll-hd.net
FINALLY..........

Our Trust’s Voluntary Transport Service is looking to recruit additional drivers to join their team. This is a challenging but rewarding role ensuring that service users and their carers reach the destination in a safe and timely manner. Service users include adults, the elderly and younger people. All voluntary drivers use their own vehicles and receive expenses. The service operates Monday to Friday and covers all units within the Leicestershire Partnership NHS Trust throughout Leicestershire, Rutland and occasionally beyond.

If you enjoy driving, meeting people and are looking for a rewarding role this may be the perfect volunteering opportunity for you.

Please contact Tom Pap, Voluntary Services Transport Co-ordinator on 0116 225 6721 or Caroline Hallam on 01509 561615 for further information.

More information about volunteering with our Trust can be found at http://www.leicspart.nhs.uk/_Involvingyou-Volunteering.aspx

LEICESTERSHIRE HUNTINGTON’S DISEASE SERVICE

Mill Lodge
Mill Lane
Kegworth
Derby
DE74 2EJ

Tel: 01509 561615    Fax: 01509 561646
www.leicspart.nhs.uk