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Danielle Carr and Mark Ford

### Head Office Changes – meet the Operations Team!

As you will know, Karen left us as Office Manager in February after working for the organisation for nearly ten years. It was great working with Karen and we miss her dearly. We took this as an opportunity to make some changes to our Head Office admin team. We are now the Operations Team and are here to support the SHDAs, fundraising and communications teams, branches and support groups and Executive Council. The team consists of myself, Danielle - Operations Co-ordinator, Anna Donnelly - Executive Assistant, and Mark Ford - Operations Officer and our new Operations Assistant, Mathew Howarth, who will be joining us from 14 May 2018. Mathew is coming to us from the North West Air Ambulance charity and is bringing some great skills and experience with him. Please get in touch with us if there is anything you may need or unsure of and we will be glad to help.

Danielle, Operations Co-ordinator

### News from the HDA

#### Do you provide vouchers for welfare grants?

If you process applications for welfare grants for people in your area, did you know you can order vouchers online?

For welfare grants provided centrally, we use **Charity Gift Vouchers Ltd**. The vouchers/gift cards cover many stores, including Argos, Currys/PC World, Tesco Direct and many others. The web address is: <http://www.vouchers4charity.org.uk/>



#### Changes to group committees

If there have been any recent personnel changes in your committee or changes in contact details, please let us know, by emailing [branch@hda.org.uk](mailto:branch@hda.org.uk), so that we can update our records.

Thank you!

#### Year End Branch Returns

The branch returns documentation has now been sent to all branch treasurers. If your branch treasurer has not yet received the information, please let us know, so we can get this sent on to you. You can email [branch@hda.org.uk](mailto:branch@hda.org.uk), or phone **0151 331 5444**. All branch return documentation needs to be sent back to us by **4 May 2018**. Thank you!

#### Operations Team - what we can do for you

Just a quick reminder that if you need leaflets, posters, compliment slips, letterheads etc, please let us know. We can send you out the updated versions of these documents. Branches and support groups should no longer be using these documents if they contain the old logo/branding.



Huntington's Disease Association

## Huntington's Disease Awareness Week is coming!

This year the theme for Huntington's Disease Awareness Week is *Shine a light on Huntington's*. This year's awareness week runs from **14 - 20 May** and there are lots of ways you can get involved.

### #LightItUp4HD

Join the international Huntington's community by encouraging a local building or landmark to light up pink and green in HDA colours.

Why not light up a window in your own home? Request your #LightItUp4HD pack by email [events@hda.org.uk](mailto:events@hda.org.uk) or call **0151 331 5445**. (Packs include one pink and one green battery operated tea light, two candle bags and an awareness poster.)



### Plan an awareness week event

Help raise funds and awareness of Huntington's disease in your local community - we can provide leaflets, balloons and stickers to help spread the message. Contact [events@hda.org.uk](mailto:events@hda.org.uk) or call **0151 331 5445**



### Get involved online

Keep an eye on our website, Facebook and Twitter for ways you can help raise awareness online with your networks in the lead up to and during awareness week – [www.hda.org.uk](http://www.hda.org.uk)

## Events



### A date for your diary

This year's **Family Weekend** will be held on **Friday 12 - Sunday 14 October** at the Radisson Blu Hotel, East Midlands Airport, Derby.

We hope to see you there! Booking information will be released in the summer.

Take a look at  
[www.hda.org.uk/events](http://www.hda.org.uk/events)  
to see all the current  
HDA events

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## General Data Protection Regulation – important changes

### General Data Protection Regulations (GDPR) are coming soon...

A lot has changed since the Data Protection Act 1998 - in particular the technologies that can be used to communicate. Online communication creates a host of new issues in protecting personal data which were not previously covered. These are now reflected in the GDPR.

#### The date for compliance with GDPR is 25 May 2018.

Put simply, data protection is about keeping personal data safe, and being fair and transparent in how you work and use personal data.

The first question many people ask about GDPR is, given that it is a European Directive and the United Kingdom has voted to leave the European Union in 2019, will GDPR still apply? The clear answer is YES and the Government has made it clear that GDPR will become part of UK Law in May 2018 and will remain in force post-Brexit.

At the HDA we hold personal data in order to deliver our advisory services, membership, fundraising and communications, and these changes will have an impact on the information that we process and store. We now have a GDPR Working Group and a dedicated Project Coordinator in place to support the HDA on the journey towards GDPR compliance. As part of this resource we will be providing support and guidance to branches and support groups to help ensure that your future communications and operations meet with the changes in regulation.

If you collect personal data in the running of your branch and support group, then GDPR will apply to you.

Some of those key changes that will affect you as a branch or support group:

- ⇒ Branch organisers need to tell people more information about what they will do with the personal data they collect
- ⇒ Groups cannot keep individuals' personal data for longer than is necessary. You need to inform people how long you will keep their data for and cannot simply keep it indefinitely. To achieve this the HDA will be providing groups with an updated data retention policy.
- ⇒ Groups will need to adopt a Privacy-by-Design approach to processing and storage of personal data. This could be effectively achieved through consolidating the personal data that you hold into one place. The HDA will provide guidance on tighter controls and security on where this personal data is stored.

Whilst the changes in the regulation may appear complicated it's simply about protecting the rights of individuals in how their personal data is used and stored. This is a principle that we are sure you will all support.

For further information:

Ewan McHenry, Project Coordinator

Email: [ewan.mchenry@hda.org.uk](mailto:ewan.mchenry@hda.org.uk)

Tel: 0151 230 2171 / 07841 037625



## Website

### Update on plans for the HDA website



Our new website has been up and running for a few months and we're excited to look at next steps to improve the website even further. An important part of this is how it can help branches and support groups and we look forward to talking to you about this in the future. The branch events calendar will be up and running again shortly.

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## Update on the Care Home Accreditation Scheme

### Care Home Accreditation Scheme Update

Progress with the Care Home Accreditation Scheme continues and the project has been extended by an additional three months to enable the care home pilot exercises to be completed.

The scheme now has a name thanks to the input of those who participated in the workshops at the branch and support group events. The three most popular names were voted on at the Family Conference in October 2017. Once the full scheme is launched it will be known as the Huntington's Disease Association **Quality Assured Scheme**.

We delivered a care home conference to over 40 delegates in October 2017 in Birmingham which highlighted that there is support amongst care home and care home providers for the Accreditation Scheme.

We will be delivering two care home pilots - one in England and the other in Wales - to reflect the differences in how regulatory assessments are delivered and the variances in how care services are commissioned.

The engagement exercises undertaken last year generated a huge amount of invaluable information on your experiences and knowledge which is reflected in the accreditation scheme as it moves forward towards its launch. We will be providing further additional information on those issues that were highlighted at a later date.

The basis of any accreditation scheme is to quality assure or measure a service against an agreed set of the standards and to achieve this through the Accreditation Scheme we have devised a set of Standards of Care to assess the care given in care homes and how the homes are run. These standards were devised through those engagement exercises that many of you participated in last year, input from Specialist HD Advisers, input from other professionals and sharing the proposed standards with care homes. To identify the core specialisms in caring for those affected by HD we have identified eight core standards that we will be assessing:

- ⇒ Governance
- ⇒ Staff
- ⇒ Meeting nutrition, hydration and oral hygiene needs
- ⇒ Behaviour & Cognition
- ⇒ Cooperating with other professionals (partnership working)
- ⇒ Working together - involving others (where permission is granted)
- ⇒ Provision of appropriate equipment & strategies for its use
- ⇒ Communication

For further information:

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## Update on support for young people



We are currently advertising for a Youth Worker for South England and South Wales. In the meantime, James O'Connor, our Youth Worker for the North of England and North Wales, is working with families across England and Wales. If a young person in your area needs support please get in touch with James.

Email: [james.o'connor@hda.org.uk](mailto:james.o'connor@hda.org.uk)



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## Branch and support group events success!

### Shropshire and Mid Wales branch

A Christmas raffle held at The Swan Inn in Ellesmere, raised a staggering £1000 for the Shropshire and Mid Wales Branch.

Huge thanks to Landlord & Landlady Steve and May Newton, their customers and local businesses, that supported the event.



**Do you have any news to share ?**

**Please email [info@hda.org.uk](mailto:info@hda.org.uk) so we can share the good news of your successes.**

If you have any suggestions for what you'd like to see in future branch newsletters please email

[info@hda.org.uk](mailto:info@hda.org.uk)