

This Month's Spotlight! All-Party Parliamentary Group Meeting February 2020, Alison Railton, Public Affairs Manager



Last week the All-Party Parliamentary Group (APPG) on MND met in Parliament to discuss our *Scrap 6 Months* campaign on access to welfare benefits for people who are terminally ill. At the meeting Becky Gatenby from Bradford gave an emotional speech about her father's attempts to claim Universal Credit after he had to give up work due to MND. Becky spoke to a record number of MPs and Peers about how her father had struggled with the welfare system. Thank you to all our supporters who emailed their MP about the meeting. A fantastic 1,300 of you took our e-action, which is another record!

It was also the APPG's AGM and the officers for the Group were elected for the coming year. You can read more here <https://www.mndassociation.org/scrap-6-months-campaign-discussed-in-parliament/>

Jessica Morden MP also raised our Scrap 6 Months in Parliament the following day and paid tribute to the work of former APPG chair Madeleine Moon. You can watch Jessica's speech here <https://parliamentlive.tv/event/index/d8adba1a-95dc-4cc1-a357-5ece62d775f1?in=13:13:01&out=13:14:42>

**Campaigns Contacts Day Susie Rabin,
Head of Policy and Campaigns**

If you haven't yet booked, there's still time to book your place at the next campaigns day on **Saturday 28th March at NCVO**, near King's Cross. This is a great opportunity to meet up and network with other campaigners, meet the new members of the team, and look at how to work with parliament, our next steps on Act to Adapt and discuss improving communications and engagement. Please RSVP to Joe by 2nd March on joe.dunne@mndassociation.org

If you are aware of any local consultations in your area please do let us know. It's always handy to hear what changes are being proposed locally and we might want to send in a response. Email Daniel Vincent, Senior Policy Adviser, daniel.vincent@mndassociation.org

A New Face at MND Association

Francesca Monticelli, Senior Campaigns Advisor

Hello, I'm Fran. I've joined this week as the new Senior Campaigns Adviser.

I've spoken to some of you already but for those who don't know... I am Italian but I've lived here for almost 8 years and I've just recently finished a Masters in Public Health. I have quite a bit of grassroots campaigning experience within the realm of housing, mainly with the London Renters Union and Medact London. The volunteering I do with the LRU is based in Hackney, focused on union member solidarity and organising local campaigns within the borough to support members with housing issues (these can range from evictions to house repairs). The aim is to collectively stand up to rogue landlords and estate agents. I am also volunteer Coordinator of Medact London. I work with a group of healthcare professionals to campaign on the intersection between bad housing conditions and health, by mobilising the healthcare voice. This intersection between housing and health campaigning I believe is of particular relevance for the Association.

I'm excited to work with you all and meet you soon!



General Election Next Steps *Alison Railton, Public Affairs Manager*

Thank you to everyone who joined the campaign calling on their parliamentary candidates to pledge their support for the Scrap 6 Months campaign. Ahead of the general election, over 12,000 emails were sent by our supporters, over 800 candidates pledged their support to Scrap 6 Months, and nearly 80 are now sitting MPs.

Although the election is now over, our campaigning continues. We will now call on the new Government to ensure it honours the commitment made by the Department for Work and Pensions in July 2019, to review how the benefits system supports people who are terminally ill. This review must be made an urgent priority. In the coming weeks we will also engage to promote our key asks for people affected by MND.

Our priorities for the new Government are:

- ⇒ Scrap the 6-month definition of a terminal illness for "the purpose of accessing benefits, so that people with terminal illnesses can access their benefits quickly and sensitively
- ⇒ Urgently develop a fair and sustainable funding solution to the social care crisis, covering both working-age adults and older people
- ⇒ Provide more funding for accessible homes to be built and more funding for home adaptations
- ⇒ Prioritise the needs of unpaid carers and ensure they get the support they deserve
- ⇒ Develop a funded MND research strategy, to help accelerate progress towards a world free from MND."

Another New Face at MND Association

Joe Dunne, Policy and Campaigns Assistant

My name's Joe and I'm the new Policy and Campaigns Assistant here at the MND Association. I've just come from a post as Project Officer at The Social Change Agency in Kings Cross, where I supported a number of projects including the Department for International Development's UK Aid Match programme, a women's leadership conference with the Clore Social Leadership Group, and the development of best practices for social media campaigning. Before then I worked in financial remediation, investigating complaints against the Royal Bank of Scotland concerning their restructuring unit after the financial crash.

In my spare time, I volunteer running Consent lectures in schools, working with teenagers through issues of sexual harassment and assault, and its structural causes.

I'm really excited to be here and to get to know you all soon!



Act To Adapt *Raj Johal*

For people with MND, getting the home adaptations they need quickly and easily is vital to ensure they can live safely, independently, and with dignity in the time that remains to them. However, there are significant challenges many people face in adapting their home, including cost, length of time taken, and poor information about the process.

With phase 1 of our Act To Adapt campaign, we hope to build awareness and engagement on this matter. We will do this by with two easy online actions for all supporters to get involved, they are:

1. **'Have Your Say'** - We encourage people living with and affected by MND to share their experiences of housing adaptations and encourage other supporters/stakeholders to share a message about their vision for accessible housing for people with MND and why this matters to them. The power of sharing stories is crucial to the campaign, it will help raise awareness, influence decision makers and

inspire support for our campaign.

2. **'Email your councillor'** – a simple ask from supporters to councillors to read the published A2A report, share with colleagues and link to the 'Have Your Say' action and encourage councillors to read the stories and leave a message of support.

The second phase of Act To Adapt, due to launch in May of this year, will involve directly influencing local decision makers to improve their systems. We are setting up an Advisory Group to support the development of phase 2. Membership of the group will include: a small group of Campaigns Contacts who expressed interest at the October Campaign Contacts day, Service Development Managers and Area Support Co-ordinators. They will help to develop our approach and resources to support regional staff, Campaigns Contacts and other volunteers to engage with local authorities on Act to Adapt.