**Neurological Alliance of Scotland**

**Members’ Meeting**

**Online via Zoom**

**17 November 2021, 10.30 – 12.30pm**

**Joining details**
<https://us06web.zoom.us/j/94714088916>

**Members in attendance:**

Alison Love – Ataxia UK

Alistair Haw – Scottish Huntington’s

Anna Telfer – Epilepsy Scotland

Avril McLean – Action for ME

Ben Peter – Scottish Huntington’s

Carol Cochrane – Brainstrust

Charlotte Encombe – MSTC Lothian

Colette McDiarmid – MND Scotland

Dawn Golder – FND Hope UK

George Allan – Scottish Post Polio Network

Gerard Anderson – Child Brain Injury Trust

Karen McCurry – MSTC Argyll

Keith Park – MS Society

Leigh-Ann Little – The Oxygen Works

Mary Ramsay – Scottish Tremor Society

Melissa – Tourette Scotland

Michelle Keenan – Edinburgh Headway

Morna Simkins – MS Society

Philip Robinson – Lanarkshire Epilepsy

Rona Johnson (**Vice-Chair**) – Epilepsy Scotland

Robert Music – The Migraine Trust

Tanith Muller (**Chair**) – Parkinson’s UK

Scott Coyne – Epilepsy Connections

Stoo Brown – ME Action

Wendy O’Mant – Ataxia UK

**In attendance:**

Ben Macpherson MSP – Minister for Social Security and Local Government

Fran Iwanyckyj – Scottish Government

Matthew Duff – Scottish Government

Alice Struthers – Programme Director, NAoS

Charlotte Sarrau – Administrative Assistant, NAoS

**Apologies**: John Watson – Stroke Association

**Agenda**

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| 10.30-10.40am | **1. Open, introductions and welcome from Neurological Alliance of Scotland**  | Tanith MullerChair |
| 10.40-10.50 | **2. NACNC update**The NACNC used the NAoS report on virtual appointments to influence the new clinical guidance received by health boards. Established the principle of asking patients what appointment format suits their needs – shared decision with clinician. Shows members’ work in getting answers to survey has led to practical and positive change. **Round 3 funding** of the Neurological Framework fund is about to open. Waiting for a website to go live to showcase results of round 1 and 2. This will be part of the ScotGov’s “learning network” to support future applicants.Thefocus of the fund is Commitment 9 of the Framework. NAoS raised concern with ScotGov that this could fund generic neuro services at the expense of specialist ones. Government's answer: this provision will be in addition to specialist service rather than instead of them. But concerns remain about how this will play out in practice.Applications will close at the end of January.Vice-Chair: ScotGov said they’re working with child health team to develop a paediatric supplement. But haven’t said if there is any funding committed to the supplement.Issue of specialist nurses will be on the agenda at next NACNC meeting. Raised that the UK government is committing £375M to neuroprogressive conditions funding – it is unclear if there are any consequentials for Scotland. UK funding seems to be mostly focused on Dementia and MND. Met with Neuroprogressive and Dementia Research Network last week. Research agenda stepping up – conference in Glasgow and online on 3rd December. | Tanith Muller  |
| 10.50 – 11.20 [Jamboard](https://jamboard.google.com/d/1A2kycG_0rOZtaWIabWHd9jf9PQ_BId-2Y3FTpJx0X2w) | **3. Campaign Brainstorm (March 2022)**We want to launch a campaign to tie in with Brain Awareness Week 2022 (March 14-20th)Proposed theme: being heard/not being listened toTask 1 CAMPAIGN THEME: 10 minutes[Jamboard](https://jamboard.google.com/d/1GClindZQ5zMVbXQ4KpaWlz7Iypvu4o4turZiYgXUaoU) Task 2: WHAT SUCCESS LOOKS LIKE: 10 minutes[Jamboard](https://jamboard.google.com/d/1A2kycG_0rOZtaWIabWHd9jf9PQ_BId-2Y3FTpJx0X2w) Members split into 4 breakout rooms to discuss. Written summaries of each room’s discussion to follow. | Alice Struthers  |
| 11.20-11.25 | **4. CYP SIG update**Members are very welcome to join the group. Looking for a new secretary. Frustration among members at the lack of progress on the ScotGov’s paediatric supplement**.** Would like to contact the clinical priorities team to ask for progress update and emphasise the need to respect children’s rights. Also ask whether there will be funding attached to the supplement after its publication. | Stoo Brown |
| 11.25 – 11.35 | **5. PES update**Fieldwork has been live for 4 weeks and responses are good so far. Answers are low from clinics but QEUH (Greater Glasgow) is leading. Need to get clinics more involved.Please put the link to the survey in your newsletter and email signatures to increase visibility. You can use a link specific to your charity or use the general Neurological Alliance of Scotland link.There is a media pack available. Important to have good Scottish response because this is the first time we have Scottish data – can be benchmarked against rest of the UK, and used to influence ScotGov policy. First time we have paediatric data as well.Survey closes January 14 so keep pushing it through your own charity’s URL or the NAoS URL. | Alice Struthers |
| 11.35 | **Comfort Break** |  |
| 11.45 | **Tanith welcomes Ben Macpherson MSP to the meeting** |  |
| 11.45-12.00 | **6. Introduction to the new Scottish Social Security Benefits by the Minister for Social Security and Local Government**Ben Macpherson MSP: I appreciate the opportunity today to meet you.I want to thank you all for your contributions to date, to that shared endeavour of creating a better and effective Social Security system in Scotland. I know many of you have responded to the consultation on Adult Disability Payment (ADP) earlier this year, and been very involved in the development of the new system, throughout the process of the Bill being passed through Parliament in 2018, and everything we’ve done since then to build up the agency and deliver the new system.In the next 10 minutes I want to give you an overview of what we’ve achieved to date, then move on to what will be introduced in the coming year, including Adult Disability Payment, which I know is of particular interest to all of you on this call.Our new agency, Social Security Scotland (SSS), is now delivering eleven benefits, seven of which are brand-new in the UK. We also continue to provide support through local authorities – the Scottish welfare fund, discretionary housing payments including mitigating the bedroom tax, and council tax reductions which are supporting many of those on the lowest income in Scotland.Over the last year and a half, despite the challenges due to the pandemic, we have still introduced four new benefits including a Scottish Child Payment which is a key part to eradicating child poverty in Scotland.In addition we introduced specific one-off payments to provide additional support, including paying around 90,000 unpaid carers an additional £230 carers supplement last year, and we will do that again this year, thanks to Parliament passing an Act in recent months, and this payment will be facilitated in December and those who are entitled will receive it at that point. We also launched a pilot of Child Disability Payment (CDP) that has been successful – the rollout across Scotland will take place on Monday 22 November which is a significant milestone in the building up of Scottish benefits and Social Security provision. Initial feedback from the pilot has been extremely positive, and we will continue to collect feedback from clients to make sure we learn what we need to, to make improvements where appropriate, and to fulfil the values of fairness, dignity, and respect.We will also pay Child winter heating assistance for the second year, from late November onwards, and we’ll be extending eligibility to severely disabled young people who receive Personal Independence Payment (PIP). This will be an extension of 5,000 more people receiving that. We will also make a double payment of Carers Allowance supplement of £460.80 in December to ensure we continue to support people during what is an extremely challenging time for many.In 2022 we will launch ADP in replacement to PIP. The pilot will launch in spring next year, before rolling this out across Scotland by summer 2022. This will be our biggest and most complex form of assistance to date. And again a really significant milestone in the delivery of Social Security and the development of the agency.Also this year, of pertinence to what you’re considering, we began our really ambitious programme of case transfer – transferring those in receipt of disability benefits from DWP to Social Security Scotland (SSS). We began that transfer in mid-October, which in the coming years will see us move the awards of around 700,000 existing clients from the DWP on to our Scottish systems, a really significant undertaking of the transfer of people. This will ensure we move everyone on a DWP benefit to the new system, without requiring an application or placing any burden on individuals. It is a complex and unprecedented challenge, but that hasn’t stopped us making a significant number of improvements to the delivery of ADP, while that process is under way. In terms of changes to delivery – importantly our approach is built on a foundation of trust, I really want to emphasise that point. So for example the Scottish Government has heard time and time again about the distress and anxiety that applying for PIP and going through a PIP assessment causes people. We firmly believe that listening to what clients tell us, and have told us, and collecting information from GPs, social works, carers and families, about an individual’s disability or health condition, is the best way to understand a client’s needs. And we will trust the information provided to us, and take a person-centred approach to make a decision on entitlement.I’m well-aware that clients with neurological and fluctuating conditions have not been treated fairly under the DWP snapshot judgements and one-off assessments. That is why we will make a decision about entitlement based on the information available, including information that clients share with us. Under the current arrangements, evidence from a medical professional is needed, to agree with everything someone has said about their ability, but we know that it is not always possible to provide evidence from a medical professional about every aspect of one’s disability. And that is why for ADP, the information we will seek only has to generally support the needs that clients describe in their application. Lots of people will be able to provide supporting information like support workers, personal assistants, and nurse practitioners. And only where we cannot make a decision using this information, will we then at that point invite clients to a consultation. It will be a discussion between a practitioner who is employed by SSS, so *not* someone from the private sector like with PIP. And if the consultation relates to a mental health condition, the practitioner will have experience working in mental health. We are also not going to carry out any functional or physical examination such as grip strength tests, or the mental health examinations. These kinds of functional examinations that are carried out in PIP assessments are unfair, they are unreliable, and they do not treat people with dignity and respect. That’s why I am confident that the approach we are taking, with no one being required to attend a face to face DWP-style assessment, will make a real difference to people with neurological and fluctuating conditions.Another change we are making to ADP is to the length of awards. We are proposing that awards will not have an end date, instead a date will be set for an award to be reviewed, to make sure that the client is still getting the right amount of ADP. Where a person’s needs are unlikely to get any less, a review date will be set between 5 and 10 years time. When a review is carried out it will be a light touch review, and we’ll only contact the client where necessary.So ADP will see an end to the stress and anxiety of continual reassessments, clients will no longer be asked to tell their story over and over again, and we are very clear on that point. Finally I want to set out to you what happens next.We want to make sure that the rules for ADP will work for the people who will receive it. I and the Cabinet Secretary believe that the changes we are making with ADP following the launch of the pilot of CDP earlier this year, will result in a meaningful and positive difference to people applying for and receiving disability assistance.However, I know there are a range of improvements that people, and that includes some of you on this call, are eager for us to make, that we are not yet in a position to introduced, because of the need for safe and secure transition from PIP to ADP to ensure that we protect people’s existing awards and payments, including crucially their passported elements and entitlements from the DWP that ADP will provide. Therefore within a year of delivering ADP, we are proposing that a review takes place, independent of the Scottish Government. This means we will have had an opportunity to learn from the first year of delivering payment, and also to collect information on how it is working. We will establish a group to carry out the review and they will seek input from people with a wide range of experience, including of course disabled people. We expect this review to identify any further improvements that we could make to ADP. The review is something we regard as very import to consider the progress made and to look ahead into any improvements that can and should be made. The review will also be a chance to look at the many improvements that we will have made, that we are making, and to understand how they are working in practice.So I hope what I’ve said has provided you with some assurances that we are taking a very different approach to the DWP. I want to emphasise that we will continue to look for ways to improve, beyond the launch of the new forms of assistance, and that we will continue to work with stakeholders like yourself, and people with experience of the system we currently have, and of the system we are creating. I hope it’s been helpful to take you through what we’ve done, what we are going to be doing in the year ahead, and going forward how we will consider matters and working collaboratively and with engagement of those with the experience to how we continue to build the best system that we can for social security delivery here in Scotland. Thanks again for the opportunity to be with you today, and I look forward to hearing your views and any questions you may have. | Ben Macpherson MSP  |
| 12.00-12.20 | **7. Q&A**Essential Tremor: Will there be an age limit on being awarded ADP?**Minister**: We are keen that when people are up for PIP reassessment, they get transferred to SSS. Some conditions would be reviewed every 5-10 years, but we are still considering indefinite awards, and will be updating Parliament in due course. Regarding the age limit, the eligibility criteria will be the same as PIP at first, until people are transferred to ADP.Chair: Is the Scottish Government communicating with current claimants to reassure them about their claim? **Minister**: The complexity of the devolution settlement and social security across the UK is a challenge. With CDP we want to raise awareness of the benefit being live, so that eligible people start applying. But we also really want people to know that existing claimants will be automatically transferred. So we are raising awareness that these two developments are happening in tandem. We will do all we can, through media campaigns, using national media, communicating with local government, MPs, statutory organisations, and yourselves as key stakeholders – your networks will be really important. Scottish Huntington’s: What assurances can the Minister give that SSS is committed to engaging with the support community? What kind of referral or signposting arrangements will be put in place by SSS, when it identifies that claimants need support or advice outwith the service they provide?**Minister**: The agency will undertake a level of signposting, in particular the local delivery teams which will be out in communities across Scotland. There is a challenge in terms of giving advice or direction on reserved benefits. We work collaboratively with partners, e.g. Citizens Advice Scotland and organisations you represent. There is a strong commitment to create the best person-centred approach that we can. We aim to reach a “no wrong door” position where people who access a public sector service can be directed towards support elsewhere, and third sector referrals can be part of that.**Written response to follow.**Epilepsy Scotland: Under the current DWP system, there is a high rate of decisions being overturned at tribunals, at a high cost for the state and causes significant stress for the claimant. Under SSS, how will the right decision be made from the start?**Minister**: We are listening to those with lived experience of current system, to make sure our system works effectively. I listed some of the changes we are making to the approach and how individuals come through system. We will only be requiring one piece of supporting information, and we will be looking to give people the support they need rather than look for reasons to reject their claim. We know the DWP approach isn't working so we are determined to get our decisions right from the start. **Matthew Duff**: We are creating a more robust, fair and dignified decision-making process. We know the DWP gets it wrong and their system puts a lot of stress on the claimant. Snapshot assessments will not happen especially when people have multiple and/or fluctuating conditions. In asking for supporting information, we will have working links with local authorities and the health sector. Without automatically asking to speak or see the client, the assessment will be carried out by a practitioner and done in a way that suits the patient.We will be moving away from medicalised assessment to a person-centred approach to address the whole range of needs of the patient.**Minister**: There is a very robust and thorough training process at the agency for the people who will deliver it. I have sat in on a training session to get reassurance that the training process is considering all these points.Epilepsy Scotland: Hearing the word ‘trust’ in a conversation about social security is new and very welcome. Child Disability Payment eligibility criteria has been moved up to 18 years old, but the maximum age to make an application is still 16. What happens to young people who develop a condition at 17? Why the discrepancy? **Minister**: There is a committee on regulation around these questions. We are making some adjustments to the regulation on the question of age. We don’t want to make too many adjustments yet, because we want to get the system established legally and practically first. But anomalies and improvements are emerging and being addressed. It’s great to hear a positive response to the different tone and approach to social security. Social security is a collective and shared investment in each other for the benefit and the common good of all of Scotland. We are determined to magnify the fact that social security is a very important and positive thing, and get away from negative way it has been portrayed and viewed.**The Minister provided a written response to this question**.Chair: Those comments are very welcome and we are hoping the reality of what is delivered will live up to the change in tone and language.If people have further questions please forward them to Alice at info@scottishneurological.org.uk and they will be sent to the Minister in writing. **Minister**: Thank you for this opportunity to speak with you. We have a shared interest in getting this right, we all want to see Scottish Social Security succeed. Your input into the consultation has been very appreciated. I would like to stay in contact with you and keep working together.  | Ben Macpherson MSP  |
| 12.20-12.25 | **8. AORB**Proposed Assisted Dying Bill will be discussed at the next meeting of Policy group on Wed 24 November.Update on the Focused ultrasound treatment campaignEssential Tremor: Rhoda Grant MSP is working with Mary Ramsay in the Scottish Parliament on making Focused ultrasound treatment available for essential tremor on NHS Scotland. Waiting for Petitions Committee on when it will be heard in Parliament. The Deputy National Clinical Director Dr John Harden would like to meet Mary and Ian Sharp to discuss the progress made so far. Tom Gilbertson (neurologist in Dundee) will be looking to involve other people with neuro conditions that could benefit from the treatment. There is still a case for NHS NSD to create a Scotland-wide service for essential tremor focused ultrasound treatment. NAoS is involved because part of our remit is to support members where they have limited capacity to campaign; but also because of the potential for focused ultrasound to be used to treat other neuro conditions. | Members |
| 12.30 | **9. Date of next meeting and close**Members meeting: Wednesday 23 February 2022, 10.30-12.30. Followed by Exec meeting, 12.30-1.30pm**.** | Tanith Muller |

Following the Members’ Meeting there will be an Executive meeting. All members are welcome to stay on as observers.