MEETING NOTE Thursday, 13 February 2020

INV/1088/2020 Roy Beggs MLA and Haemophilia NI

INV/1214/2020 Martina Anderson MLA and Families & Friends of Haemophilia NI

Meeting with Minister Swann

TITLE/ORGANISATION:	DOH Health Protection Branch			
VENUE:	☐ **e.g. PB**	D2 Lecture Theatre	☐ **OTHER:**	Castle Buildings
LIST OF ATTENDEES:	Martina Anderson MLA GRO-D - Co- Chair F&F GRO-D Co-Chair F&F GRO-D GRO-D GRO-D GRO-D Roy Beggs MLA GRO-D – Chairman, Haemophilia NI GRO-D Haemophilia NI GRO-A Haemophilia Society GRO-D			
☒ **Minister**	☒ **Spad**	☐ **PS**		
OFFICIALS:	Seamus Camplisson Lesley Heaney			
OTHERS:	Jackie McIlroy (part attendance)			

KEY POINTS DISCUSSED:

The Minister set out the current position in relation to financial support:

- interim payments announced on 27 January was a decision Minister had taken on his own and he apologised if it was taken the wrong way
- commitment to spending remaining allocation from January monitoring before end of the 2019/20 financial year

- notification of allocation came late and no guarantees for recurrent funding next year
- intention to build a strong robust business case to secure recurrent funding
- looking at the other schemes and considering options over next 2-3 weeks
- important he meet infected / affected to hear their stories first hand
- made clear he wanted to listen to everything the Groups had to say; he is on their side and they have his full support
- glad to hear their stories and intends to meet the groups again once the first phase work is compete

In terms of action by Govt, attendees:

- acknowledged the action that the Minister is taking and respect the one-off payments that have been made and would welcome further payments
- appreciated the Minister taking the time to meet both groups
- disappointed at lack of action by the Dept before Executive was restored
- expressed disappointment that full £1m allocation from DoF had not been used – described this as insulting and accused Perm Sec of "playing fast and loose" with public money that was meant for beneficiaries of the Infected Blood Scheme.
- asked where resolving infected blood was on Minister's list of priorities
- disappointed that views of infected / affected have not been sought, they have been "left out" or "kept in the dark"; expressed a desire to be kept involved in the process of reform.
- expectations have been "raised and crushed" several times over - concerned that expectations will be crushed again
- disappointed that Perm Sec had not attended hearings or viewed witness statements; appealed to the Minister to watch the evidence to the Inquiry in Belfast
- one individual asked the Minister to read his full statement and oral evidence.
- said that previous SoS had used them as "a political football"
- felt that DoF Minister and Perm Sec had listened and had taken control but that DoH decision to release 60% of the allocation left them disappointed
- felt they should not have to chase the Govt for action, the Govt should be proactive in taking action.

In terms of the Infected Blood Support schemes across the UK, attendees:

- stated that if NI adopted best aspects of UK schemes, problem would be solved
- highlighted that the scandal had happened under UKG (not devolution)

- pointed to NDNA which commits to bringing about *"parity in financial support to victims of contaminated blood in NI with those in England"*
- felt that Govt is treating people unfairly; all victims should be treated equally across the UK; described it as a "human rights issue"
- Want parity with England on regular payments first, then other areas of scheme e.g. support to bereaved can be considered in phase 2

In terms of the impact of being infected and / or affected, attendees:

- highlighted the IBI Psychological Report which said treatment can cause dementia
- felt they have battled with their health for their whole lives
- said they have opened up and told their stories to the IBI and are now exhausted
- said that one person is dying from infected blood every four days: "time is life"
- expressed an aspiration to set up a victims' forum
- felt a sense of frustration that they are victims in a process – the IBI unlocked this and now they need support and aren't getting it.

Each member of the group recounted their personal experience. For those infected, this included:

- **impact on physical health** - being infected with Hepatitis or HIV at a young age; side effects of treatment, being fearful that current treatment is a risk, some have to be checked every six months for signs of cancer
- **impact on family life** – relationship / marriage breakdown, ex-partners fearing infection, having to wash children's toys, parental guilt because haemophilia is an inherited genetic condition
- **impact on career** – loss of job, successful careers ended, continuing to work but having to keep diagnosis a secret
- **impact on finances** – loss of home, loss of income, unable to get life insurance, unable to support family
- **impact on mental health** – anxiety, depression, suicidal ideation, suicide attempts, fear of "what is coming next", never cleared as virus lies dormant ("non-detectable"), some receiving psychological support, while others cannot travel to Belfast
- **fear** – particularly among younger haemophiliacs that they will end up the same as older relatives who were infected
- **stigma** – having to endure stigma their whole lives, dentists not wanting to provide treatment, fears of risk, have to carry a form saying they may have vCJD, stress of giving evidence to the Inquiry and whether to do this anonymously

- Many described themselves as “lucky” or “one of the lucky ones” as they were still alive; one individual diagnosed with HIV aged 4 described themselves as “incredibly lucky to be here”, while others said they were “very grateful” to have come through their illness, treatment and survived as many have died and been unable to tell their stories

For those affected, this included:

- **impact on career** – having to leave job to care for loved one
- **impact on family life** – can’t afford to be unwell, unable to have children or adopt, spouse / partner / children having to be tested
- **impact on mental health** – losing one or more close relatives, fear that the next infection could lead to organ failure, having to plan funerals for a loved one several times
- **stigma** – made to feel like diagnosis is a “dirty secret”, some didn’t tell their spouse and received treatment in secret
- felt their loved ones were “treated like guinea pigs” or just a “statistic”; loss of trust in the healthcare system

The meeting was emotional for many in the room and Martina Anderson asked the Minister to invite a professional in for support for attendees. Jackie McIlroy joined the meeting and afterward spoke to a number of individuals.

ISSUES AGREED:

- Will meet again when phase 1 is complete, in the coming weeks.

ACTION POINTS / OFFICIAL RESPONSIBLE:

- Will meet again when phase 1 is complete, in the coming weeks – LH

NOTE WRITTEN BY:	**DATE:**
Lesley Heaney	14 February 2020