

**IN THE UK COVID-19 INQUIRY**

**BEFORE BARONESS HEATHER HALLETT**

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**SUBMISSIONS FOR THE MODULE 4 PRELIMINARY HEARING 13<sup>th</sup> SEPTEMBER 2023**

**ON BEHALF OF**

**VACCINE INJURED AND BEREAVED UK (VIBUK)**

**UK CV FAMILY AND THE SCOTTISH VACCINE INJURY GROUP.**

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**A. INTRODUCTION**

1. The following submissions are drafted in order to assist the Chair with her investigation and management of Module 4 of her Inquiry at the Preliminary Hearing on the 13th September. We refer to the helpful note provided by Counsel to the Inquiry (CTI) dated 22nd August 2023 where necessary.
2. The UK CV Family, Scottish Vaccine Injury Group and Vaccine Injured and Bereaved (VIBUK) are grateful to the Chair for her determination of the 4<sup>th</sup> August 2023 that each group be granted Core Participant status in Module 4 of her Inquiry. They are also grateful for her recognition in that determination that these three groups are well placed to assist the Inquiry to achieve its aims by representing the collective interests of a broad spectrum of those who have been bereaved or adversely affected following a Covid-19 vaccination. The UK CV Family, Scottish Vaccine Injury Group and Vaccine Injured and Bereaved (VIBUK) are grateful to the Chair for her determination of the 4<sup>th</sup> August 2023 that each group be granted Core Participant status in Module 4 of her Inquiry. They are also grateful for her acknowledgement that these three groups represent a broad spectrum of those who have been bereaved or adversely affected following a Covid-19 vaccination, therefore, are well placed to assist the inquiry in achieving its aims.
3. The Chair has granted each of the three distinct groups Core Participant status as part of a joint grant with joint representation. We confirm that we represent all three groups, and that they wish to be referred to as the “Covid Vaccine Adverse Reaction and Bereaved”. Mr. Wilcox is the recognised legal representative for all three groups.

## **B. THE COVID-19 VACCINE ADVERSE REACTION OR BEREAVED GROUPS**

4. **The UK CV Family** is the largest support and advocacy group in the UK for those who have lost a loved one or suffered a life changing adverse reaction to a Covid-19 vaccination. They are run entirely by volunteers, all of whom are vaccine-injured or bereaved themselves. They are focused on the needs of UK based patients, providing help and advocacy and actively raising awareness amongst the British healthcare system, media and government.
5. As of August 2023, UK CV Family has more than 1,200 members and approximately 20 people join every week. Members are 75% female and 25% male, and ages range from 14-76 years old. The most prevalent age range is 45-54 years. Membership is limited to people who have had an adverse reaction from a Covid-19 vaccine. There are also two other groups specifically focusing on the needs of those bereaved by a Covid-19 vaccine, or caring for those living with the ongoing effects of an adverse reaction. The group has a strict criteria for joining. Those simply curious about vaccines or seeking information for their own agenda are not permitted to join.
6. **Vaccine Injured Bereaved UK (VIBUK)** is a group of individuals and families who have either been severely injured or bereaved as a direct and confirmed result of receiving a Covid-19 vaccine in the UK. They are campaigning for the government to reform the Vaccine Damage Payment Scheme (VDPS) because it is inadequate and inefficient. They also run a support group, offering support, guidance and raising awareness of vaccine injury and bereavement.
7. All families and individuals represented by VIBUK have suffered injuries or bereavement as a direct result of a Covid-19 vaccination. The primary causes of these injuries and deaths are Vaccine induced Thrombotic Thrombocytopenia (VITT), Vaccine Induced Vasculitis, Stroke, Cerebral Venous Sinus Thrombosis (CVST) and Guillain-Barré Syndrome (GBS). Survivors are having to cope with the aftereffects of their injuries, including brain damage and physical disablement, whilst the bereaved are struggling to live without their partners, children, or parents. All VIBUK members have confirmation that their injuries were caused by their Covid-19 vaccine.
8. **The Scottish Vaccine Injury Group** is a rapidly growing community of Scottish individuals who have either experienced adverse reactions to or who have been bereaved by Covid-19 vaccines. In a small number of instances, carers have joined the group on behalf of relatives

who are too sick to participate. The group currently has over 200 members and has core participant status in the Scottish Public Inquiry. All applicants to the group are screened rigorously to ensure that they are adversely impacted.

9. Collectively, we estimate that these three groups (allowing for some overlap) represent at least 1,350 Covid-19 vaccine adversely impacted individuals. We have no way of knowing exactly the numbers that have been adversely impacted but it should be assumed that there are others who have not yet found a support group.

### **C. THE EXPERIENCE OF THE VACCINE INJURED AND BEREAVED**

10. The individuals within the groups that we represent currently fall into two categories, firstly fatal cases and secondly significant injury cases.
11. Regarding the fatal cases, for example, from VIBUK, these include: Lisa Shaw, Stephen Ward, Dr. Stephen Wright and the partner of Vikki Spit (Zion) who all lost their lives due to Vaccine Induced Thrombocytopenia and Thrombosis (VITT), as did Neal Miller and Lucy Taberer. Louise Moore and Victoria Roberts developed blood clots in the heart, brain and lungs respectively. Kenneth Purnell lost his life due to vaccine induced Vasculitis. The partner of Michael Cornwell died due to bilateral cerebral venous thrombosis. Margaret Bailey lost her life from a suppressed immune system due to developing stage 4 lung cancer. From UK CV Family, Alexandra Kelly has lost her mother to pneumonitis caused by the Covid vaccine. And with Scottish VIG, there are a number of bereaved families who were denied the required investigations because the deaths occurred during lockdown at home.
12. Regarding the significant injury cases, individuals within all three groups have developed a variety of conditions including VITT, Amputation, Cerebral Venous Sinus Thrombosis (CVST), Guillain Barre Syndrome (GBS), Mast Cell Activation Syndrome, significant Vision Impairment, Rheumatoid Arthritis, Pericarditis, Myocarditis, Chronic Fatigue Syndrome, Tinnitus, Heart Issues, Chest Pain, Brain Fog, Weakness in arms/legs/hands/feet (potentially undiagnosed GBS), or have suffered Pulmonary Embolism or Heart Attacks. This is not an exhaustive list.
13. Many of our clients have experienced delayed diagnoses, which has resulted in permanent damage, for example permanent nerve damage, cardiac fibrosis, heart failure and amputation. Furthermore, people have suddenly died due to delayed diagnoses and/or treatment. Each individual group is able to provide specific case studies for the Inquiry.

14. Covid vaccine injuries and bereavements have a wider impact on society as a whole, in particular the medical professionals who have been unable to work since the beginning of the rollout as they were the first to be vaccinated. Our clients can provide case studies of NHS staff who have experienced significant adverse reactions, and in some cases, death.
15. The Covid-19 vaccine bereaved have also suffered distress through delays in confirming the cause of death of their loved ones. The Chair should examine these issues, along with their broader experiences within the coronial system. Many of those we represent are still waiting for inquests into the deaths of their loved ones, some over 20 months since the date of death. This not only inflicts profound emotional distress upon the bereaved but also erodes their confidence in the accuracy of data pertaining to vaccine-related fatalities. A pertinent example is the fact that the Medicines and Healthcare products Regulatory Agency (MHRA) solely records data on reported deaths, rather than confirmed deaths.
16. In addition to their injury or bereavement, those we represent have also experienced a second trauma. A lack of medical knowledge and understanding about the risk and presentation of vaccine injury; leaving some injured people undiagnosed and without treatment. Furthermore, a prevailing institutional mindset within medical bodies and the government has been fixated solely on acknowledging the benefits of the vaccine. This has led to those reporting vaccine injury to feel disbelieved, unheard and marginalized. VITT, once recognised, resulted in psychological support being specifically added to its treatment protocol — this needs to be addressed for all vaccine-injured patients. There has been a fundamental lack of compassion shown towards these vulnerable members of our society.
17. In August 2022, the UK CV Family lost its first member to suicide, and both UK CV Family and Scottish VIG regularly deal with suicidal members. Both groups are extremely concerned that, in the absence of psychological support for their members who are now dealing with a chronic as well as stigmatized illness, this will not be the last suicide within the injured community.

#### **D. THE VOICES OF THE VACCINE INJURED AND BEREAVED**

18. Those we represent voluntarily participated in the vaccination programme when called upon. A significant number of them encountered adverse reactions following the first vaccine dose. Nonetheless, they were advised by their doctors to proceed with a second dose; their doctors not suspecting any vaccine-related connection. Consequently, many of these individuals

required urgent medical attention. It is apparent that doctors are not routinely asking patients about recent vaccinations when patients present with complicated, unexplained symptoms, unlike the manner in which they routinely inquire about recent Covid-19 exposure, other illnesses, or significant life changes.

19. The vaccine injured and bereaved are censored in their private communications on social media. Private support groups have been shut down by social media platforms and groups have to be heavily moderated to avoid language that triggers censorship algorithms. Individuals do not feel safe when communicating in what they consider to be a private forum. Such censorship is wholly inappropriate for a support group of this nature.
20. The vaccine injured and bereaved are also censored in their efforts to raise awareness of their experience through the mainstream and social media. They have faced stigma and abuse for sharing their symptoms in the context of the Covid vaccine, even being branded as “anti-vax” for sharing very real and medically proven vaccine injuries.
21. The treatment of the vaccine-injured in this country has historically been a source of shame. Neglect and discrimination have been brought to light through the Covid-19 vaccination rollout and is now resulting in serious mistrust of British institutions, in particular of the government and healthcare system. Trust is vital in the event of future health crises. In order to rebuild trust from the general public, the UK must urgently develop an effective and compassionate means of medically, practically, financially, and emotionally supporting the vaccine-injured.

#### **D. SUBMISSIONS IN RESPONSE TO THE CTI NOTE DATED 22<sup>nd</sup> AUGUST 2023**

##### **Provisional Scope of Module 4**

22. Those we represent are grateful to the Chair for the Provisional Outline of Scope for Module 4. In our submission, the Covid Vaccine Adverse Reaction and Bereaved can assist the Chair in respect of important aspects to which Module 4 relates.

##### ***Vaccine Safety***

23. We note that the questions identified by CTI at §34 of their note do not include reference to vaccine safety, we assume that this an oversight given the Provisional Outline of Scope.

24. The Covid Vaccine Adverse Reaction and Bereaved submit that the inquiry should examine whether during the Covid-19 pandemic there was a barrier to the recognition, reporting and treatment of the presentation of serious vaccine complications due to a lack of awareness, information or education on the subject amongst clinicians. They further submit that the inquiry should examine whether the Covid-19 pandemic impacted on the healthcare system's capacity to identify and treat vaccine complications as part of the examination of vaccine safety issues which will impact on public trust and therefore future pandemics.
25. The three groups would each like the opportunity, as part of the Inquiry, to present real-life experiences that represent life-changing adverse reactions that can be found as a result of the Covid-19 vaccine, and what happened following reporting. As part of investigating the topic of vaccine safety, our clients are able to give evidence of how medical professionals responded when presented with possible adverse reactions, what information medical professionals had been provided with beforehand, and how information was conveyed to other members of the medical profession as well as safety monitoring systems.
26. Our clients seek an examination into the public awareness regarding the safety profile approval process for the vaccine. This investigation should encompass any steps that might have been overlooked due to the urgency of their production, distinctions between these vaccines and previous vaccines, as well as an analysis of the documentation presented to the MHRA that ultimately resulted in their approval.
27. Our clients also request that the inquiry conduct a thorough investigation into the decision not to use alternative therapies to treat Covid-19 and instead to employ emergency regulation to roll out a new vaccine. They would also request an investigation into why alternative options are not prescribed to the vaccine injured when individuals within this community already benefit enormously from their therapeutic effects but are forced to source them privately.

### ***Reporting of Vaccine Injury***

28. This was a novel treatment on a global scale so reactions were expected. The yellow card system was not built to cope with something of this magnitude. In our submission, the Chair should examine whether there should have been a bespoke reporting system set up for this vaccine rollout that also involved a follow up to ensure the wellbeing of those who submitted a report.

29. As part of this bespoke scheme, data could have been collected from those who submitted reports (e.g. ethnicity, gender, age, medical history, blood type) which could then indicate relevant factors that could point to why particular groups reacted. The pandemic provided a one-off opportunity to monitor and record potential adverse reactions, given that they were expected. This data has not been collected.
30. The Yellow Card System should be investigated for its ease of use, especially for individuals for whom neurological functions have been impaired. Our clients feel very strongly that medical professionals should have been reporting suspected adverse reactions, rather than them having to do it themselves.
31. We have no idea how many people have actually had an adverse reaction to any of the Covid vaccines. The Inquiry, as a matter of urgency, should investigate (i) the effectiveness of a passive reporting scheme such as the Yellow Card System, and (ii) any other ways to determine exactly how many people have been impacted by an adverse reaction. For example, according to the UK government website updated on 6th April 2023, 53,813,491 people in the UK had had the first dose of the Covid-19 vaccine, and 50,762,968 had had the second. Those numbers were reported up to 11th September 2022. That leaves 3,050,523 (6%) who stopped after the first. Over three million people in the UK did not come forward for the second part of what was clearly marketed as a two-part vaccine course. The Chair should be concerned about the reasons why that 6% did not take the second dose. One reason may have been that they did not have the second dose because of how unwell the first dose made them feel.

***The Provision of Medical, Psychological, and Financial Support to the Vaccine Injured and Bereaved.***

32. In our submission, the Inquiry must also consider how the vaccine injured and bereaved have been discriminated against by the lack of medical and emotional support for their injuries and trauma. This includes -
- a. **Equal access to appropriate medical testing to help identify relatively common pathologies in post-vaccine patients** (including testing for clotting, inflammation, mast cell activation, autoimmunity, cardiovascular and endocrine, neurological, neurocardiology and pulmonary).

- b. **The provision of specialist team medical professionals** who can contribute to research and inform clinical guidelines and help direct and provide specialist care to post-vaccine patients.
- c. **Appropriate treatment of vaccine induced illnesses and injury.** While most of the common post-vaccine diagnoses have no cure, there are multiple treatments available through the NHS that can at least alleviate symptoms and improve the quality of life for patients. As this was a novel vaccine, rare adverse events were expected, therefore NICE guidelines should have been put into place prior to rollout. NICE guidelines — not just for VITT but for other conditions including multisystemic adverse reactions — should be being developed now. NHS staff should receive specific training as to how to identify and treat potentially vaccine-injured people.
- d. **A dedicated research hospital** should have been established to specifically treat or research adverse reactions. Instead, our clients have added to existing pressures on local healthcare services, with multiple referrals, doctors' appointments, and trips to A&E. This situation has led to avoidable suffering for patients, particularly when they encounter healthcare practitioners unfamiliar with how to provide assistance, resulting in referrals to consultants who have never encountered cases of adverse reactions to Covid-19 vaccines before.
- e. **Appropriate psychological and emotional support for the vaccine injured and bereaved.** The neurological and physical damage caused by an adverse reaction to a vaccine in itself can cause a chemical imbalance and brain inflammation. Added to that is the impact of living with chronic illness, and the stigma associated with vaccine injury. The mental health effects include shock, fear, anger, hopelessness, trauma, and the impact of adjusting life to accommodate injury. This may mean a complete change in physical health, mobility, living arrangements, relationships and career. Mental health organisations and individuals require specific training to deal with supporting vaccine-injuries.
- f. **Adequate financial support for the vaccine injured and bereaved.** The financial implications on the vaccine injured are significant. One survey within the injured community found that 90% of respondents had paid privately for testing and treatment, and in doing so had depleted their life savings, gone into debt or had sought crowdfunding from members of the public. It also indicated that individuals had each spent an average of £6,000 in their attempts to treat their vaccine injury, with some people spending upwards of £50,000. For many there is also a loss of income and/or an increase in caring responsibilities that has a damaging impact on household income. These challenges have arisen due to prolonged waiting lists and a scarcity of available treatments.



## *The Vaccine Damage Payment Scheme*

33. In relation to Issue 6 of the provisional scope, the Covid Vaccine Adverse Reaction and Bereaved have direct and extensive personal experience with the Vaccine Damage Payment Act 1979 (VDPA) scheme, and many actively campaign for its reform based on their personal experience of it as being inefficient and inadequate. It is their clear view that it is no longer fit for purpose and requires fundamental reform.
34. VIBUK have been campaigning for the government to reform the Vaccine Damage Payment Scheme (VDPS), part of the Vaccine Damage Payment Act 1979 (VDPA). They want the government to reform the VDPS to:
- a. **Improve the time** it takes to assess and award claims as the current process is slow and inefficient, which causes additional stress and trauma to victims.
  - b. **Remove the limited eligibility criteria for causation.**
  - c. **Change the all-or-nothing, 60% disablement threshold for an award to be made under the scheme.**
  - d. **Amend the one size fits all ‘award’/payment of £120,000** and have no upper limit.
35. VIBUK have had very little engagement from the government on the issue with many MPs completely ignoring requests for help from their constituents on the issue of the VDPS.
36. We also ask the Chair to review:
- a. The care pathway provided to ensure appropriate medical and emotional support to the vaccine injured and bereaved.
  - b. The lack of a trauma-informed approach to the claiming process, from start to finish.
  - c. The qualifications and relevant experience of the Medical Assessors employed to analyse VDPS claims and appeals.
37. As of July 11<sup>th</sup>, 2023, the VDPS has received a total of 6,399 claims related to Covid-19 vaccines, of which 2,352 have been notified of an outcome. Only 127 claimants have received an award, while 177 claims were unsuccessful solely because they did not meet the 60% disablement criteria, even though causation was accepted. This highlights the inherent shortcomings of the current "all or nothing" scheme, leaving these claimants without any compensation. By contrast, in 2019-2020, out of 70 claims, one was rejected for failing to

meet the disability criteria. 557 of the claims received have been waiting for more than 12 months, with 166 of them waiting for over 18 months to receive an outcome.

38. 96% of VDPS claims have been refused. Many have been turned down on causation despite having evidence from multiple consultants that their injuries started following vaccination, despite having received exemptions, and despite having adverse reaction to a Covid-19 vaccine recorded in their permanent medical records.<sup>1</sup>
39. Those we represent understand that the level of award for the VDPS (£120,000) was set in 2007 and takes no account of inflation. Neither does it take account of the financial reality of a family left caring for a severely injured loved one, or for those having to reshape their lives following a bereavement. This has resulted in some individuals seeking recourse through legal action as the award is inadequate.
40. Many of our clients have lost their income, in part or full, as they are too disabled or ill to work. Disability benefits take a long time to process and Department for Work and Pensions (DWP) staff are not trained in understanding the symptoms of adverse reactions to vaccines. Those harmed by a vaccine not only experience financial distress due to the loss of income but also face additional financial burdens. These include expenses such as private investigations, physiotherapy, counseling, and prescription medications.
41. A letter dated 14<sup>th</sup> October 2021 informed claimants that responsibility for managing VDPS claims would transfer from the DWP to the NHS Business Services Authority (NHSBSA) from 1<sup>st</sup> November 2021. This change led to a delay in claims processing, as it made it necessary for a new contract to go out to tender. In the interim the agreement that remained in place between the DWP and NHSBSA was that only non-Covid claims could be assessed. The new contract, however, did not commence until 24<sup>th</sup> March 2022, and medical assessments began on 23<sup>rd</sup> May 2022.
42. Those we represent also ask the Chair to consider vaccine injury payment schemes in other jurisdictions, how their criteria differ from the UK and whether the UK can learn positive lessons from that comparative exercise. These other jurisdictions include New Zealand, Norway, Australia and Canada (amongst others).

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<sup>1</sup> Module 1 Witness Statement of Vaccine Injured Bereaved UK (VIBUK), page 12, §39

## **Disclosure to Core Participants**

43. The development of the Covid-19 vaccine did not happen in a silo. Vaccines are likely to have been a central consideration for both the planning for and the response to the pandemic.<sup>2</sup> The vaccine response can be seen as a thread that runs through the Chair's inquiry and cannot be wholly separated out.
44. Those likely to be providing the Chair with evidence during Module 4 include scientific, medical, public health and data experts and agencies. It will be of assistance to the Chair to understand the readiness of the research, development and production and regulation mechanisms for the vaccine as part of that public health service response and strategy. Our clients would hope to see representatives of the MHRA provide evidence to the Inquiry.
45. The Chair has already heard evidence in Module 1 and is about to commence hearing evidence in Module 2. That evidence will inevitably shape and influence the Inquiry's understanding of evidence in subsequent modules including Module 4.
46. The Covid Vaccine Adverse Reaction and Bereaved request access to the relevant disclosure from Modules 1-2c, which on the current timetable are all due to be heard before Module 4. We would welcome an early dialogue with the Inquiry Legal Team (ILT) and CTI as to how this can be achieved.
47. We also remind the Inquiry that the applicants are from England, Wales, Scotland and Northern Ireland and therefore the issues within the Chair's scope for Module 4 must be analysed from the perspective of the UK as well as the devolved nations.

## **"Every Story Matters" - Listening Exercise.**

48. Our clients note with concern that none of Key Lines of Enquiry (KLOE's) set out at §58-59 of the CTI note seek to research the injury and bereavement caused by the Covid-19 vaccine. In our submission, the Inquiry cannot simply ignore the reality of this lived experience for an unknown number of people. The Inquiry should be targeting research and evidence that allows it to properly understand the number, nature and degree of these injuries in order to fully establish the facts surrounding them, which in turn can inform the Chair's findings and recommendations for future health crises.

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<sup>2</sup> See Witness Statement of UK CV Family prepared for Module 1, page 3 §§13-21

49. Therefore, we suggest that the following KLOE's should be included to assist the Chair with her investigation –

*1. Impact of the vaccine, including;*

- a. Experiences of vaccine-related injury and bereavement*
- b. Whether particular underlying medical conditions made it more likely for individuals to experience vaccine injury*
- c. Whether particular factors such as age, gender, race, ethnicity made it more likely for individuals to experience vaccine injury*
- d. The experience of the vaccine injured in reporting their injury*
- e. The mental health impact on those experiencing vaccine injury*
- f. The experience of any discrimination of stigma on the basis of their vaccine injury or bereavement (this can include from health care providers, employers, the media or members of the public)*
- g. The experience of the vaccine injured and bereaved in applying for/obtaining funds from the VDPS scheme.*

**Expert Witnesses**

54. The Covid Vaccine Adverse Reaction and Bereaved would be grateful for dialogue with CTI/ILT about the experts under consideration for Module 4 in order to be able give their assistance to the Inquiry at the earliest opportunity in respect of the identification of suitable experts.

**Effective Participation of the Vaccine Injured and Bereaved.**

55. We are grateful for the recognition by CTI at §66 of their note that those we represent have relevant evidence to give. We ask the Inquiry to consider from the outset how it will hear evidence from the Covid Vaccine Adverse Reaction and Bereaved as part of the oral evidence hearings. The applicants are the only individuals who can give firsthand evidence to the Chair of their experience of the vaccine injury, their experience of reporting their injury, and their experience of the VDPS.

56. We also ask that the Inquiry be mindful that our clients are significantly health impacted and/or bereaved and will need support and appropriate accommodations from the ILT to

attend hearings and participate effectively. Again, early conversation with the ILT as to how this can be facilitated would be beneficial. Specifically, we request significant dates to be provided with at least a month's notice, including submission deadlines for material such as this very document.

### **Commemoration**

57. We trust that the Inquiry will encompass in its commemorative efforts those who lost their lives and those who have endured significant suffering as a consequence of the Covid-19 vaccine. We look forward to further discussions with the Inquiry concerning potential filming opportunities.

### **Future Hearings**

58. We welcome the indication that there will be a further preliminary hearing in Module 4. Without the disclosure, it is challenging for us to comment on the proposed time estimate for the oral evidence hearings and will have submissions to make on this subject in due course.

**Anna Morris KC**  
**Garden Court North Chambers**

**Mark Bradley**  
**Deans Court Chambers**

**Christian Weaver**  
**Garden Court North Chambers**

**Terry Wilcox**  
**Hudgell Solicitors**

**5<sup>th</sup> September 2023**