



## **Inquiry: variant Creutzfeldt-Jakob Disease (vCJD)**

Submitted by Primary Immunodeficiency UK ([www.piduk.org](http://www.piduk.org))

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### **1. About PID UK**

PID UK is a national organisation working for patients is an organisation supporting people affected by primary immunodeficiencies in the UK.

Our aims are to help ensure that every individual and family affected by a primary immunodeficiency has the knowledge needed:

- To manage their condition effectively
- To ensure that their health needs are understood and addressed by those involved in policy and delivery of healthcare.

### **2. Our role in ensuring safety of plasma derived products for patients**

A large majority of patients with PIDs (approx 5000) need life-long treatment with immunoglobulin (Ig) infusions. The safety of this product is of paramount importance to affected patients who cope with the health burden of these complex chronic conditions and for whom Ig infusion is an integral and essential medicine.

To ensure safety issues concerning plasma products is maintained we work with other patient groups, both national and international and UKPIN, the professional body for doctors, nurses and scientists involved in the care of PID patients. PID UK fully endorses the work of UK PIN and their work on the surveillance of prion infection in these patients, led by Dr M Helbert.

Currently PID patients receive Ig infusions derived from plasma ONLY from non-UK sources. This was put in place following exposure of PID patients in the UK to plasma from people who went onto develop vCJD.

### **3. Response to terms of reference**

**PID UK fully endorses the response and recommendations made by UKPIN in response to this consultation.**

*3a. Are UK policies governing who can donate blood and blood products, tissues and organs sufficiently evidence-based? Is NHS Blood and Transplant overly restrictive about who can donate, or should greater precautions be taken to further reduce risk?*

The use of UK-sourced plasma would be a cause of extreme anxiety to PID patients without full mitigation of risk of prion contamination. It would be essential to have in place a prion

screening procedure. We understand that this would require a blood or urine test for asymptomatic prion infection if UK plasma were to be used in the future.

Tracking of donations would be essential to ensure traceability back to individual donors.

*3b. Is the Government and its scientific advisory structure sufficiently responsive to the threat posed by emerging diseases being transmitted through blood and blood products, tissues and organs?*

PID UK understands from UKPIN that there are currently no clear lines of communication and accountability about relaying incidences of prion infection through their study.

*3c. Has the threat of ongoing transmission of vCJD through the blood and blood product supply been adequately mitigated?*

This has been well mitigated through the use of non-UK sourced plasma. Through education of patients of the processes involved in sourcing donors and isolating Ig there is confidence within the community about its safety.

Steps to mitigate risk using UK plasma would need to include essential screening procedures for prion contamination and robust traceability mechanisms.

### **Declaration of interests**

PID UK over the last year has been in receipt of two donations from CSL Behring.