Infected Blood Inquiry

Closing Submissions

United Kingdom Thalassaemia Society

Introduction

1. This submission is made by the United Kingdom Thalassaemia Society (UKTS) on its own behalf and on behalf of its members.

2. The UKTS is the only UK wide charity supporting individuals and families affected by the genetic blood condition, thalassaemia. Officially registered in 1978, the society was founded by parents and well-wishers who first came together to support one another as parents were told their children would not live to become teenagers. The work of the charity rapidly escalated to also fund research and lobby the government, national health service, hospitals and specialists towards developing a structured treatment regime for their children living with thalassaemia. The charity governed by nine trustees all of which either live with a severe form of thalassaemia themselves or is a parent of someone with thalassaemia. The charity employs two full time and one part time staff members.

About thalassaemia

3. Transfusion dependent thalassaemia is a life-threatening inherited condition in which individuals are unable to produce normal adult haemoglobin to live. As a result of this, individuals affected become profoundly anaemic and require regular blood transfusions, ranging from every two to four weeks from infancy and depending on the severity of the case, in order to survive. Individuals living

with thalassaemia also receive chelation therapy in order to remove the excess iron accumulated during these transfusions. Without appropriate chelation therapy, excess iron could be deposited in vital organs, consequently, leading individuals to develop other livelong complications such as diabetes, osteoporosis, cardiac disease, renal disease, infertility, liver damage resulting in hepatocellular carcinoma.

4. Until 2008, cardiac iron overload and infection were thought to be the main cause of death in thalassaemia. Since then, hepatocellular carcinoma (HCC) has become a growing problem for patients who acquired a long term Hepatitis C infection.

5. As a result the current team at the UKTS (who were not being present before 2007), welcomed, facilitated, and supported the Infected Blood Inquiry to the best of their ability to ensure their members and their families affected by the infected blood scandal were not just given justice but also to ensure their voices were heard throughout the inquiry.

6. It was disappointing yet understandable for the team that despite their best efforts of trying to encourage their membership and families affected to come forward and testify, many chose not to due to the trauma of the diagnosis, the rigorous and horrific treatment regimes, experiences stigma and fatalities.

7. In most communities in which thalassaemia is prevalent, there is an enormous amount of social stigma associated with living with an inherited condition affecting the production of red "blood" cells. Within some communities, the idea of someone living with thalassaemia were inaccurately categorised as them having "bad blood". As a consequence of this, individuals would wrongly be considered as a "burden", "less than" and not "marriage material". As such, many families felt the only way to protect their loved ones from stigmatisation and social exclusion and additional psychological burden were to not disclose their children's condition to outside of their immediate family unit. Unfortunately, the stigma and belief is still present today

8. The feelings attributed to psychosocial burden due to thalassaemia were then further reinforced by the stigma associated with Hepatitis C. They combined a range of factors, including; illness related uncertainty due to their hepatitis C diagnosis, prognostic unpredictability, stigma and discrimination, as well as the previously unknown fear of transmission to others. They all cause additional stigmatisation and increased the uncertainty and negativity about the future.

9. Another attributing factor in why many individuals and families did not come forward was due to who would be blamed. Individuals and families affected spoke highly of their consultants and nurses felt that testifying would be disloyal or ungrateful to how well they were treated. They not only believed but trusted and respected the advice of their health care professionals especially as there was no alternative treatment to blood transfusion therapy and to them the only other option was death.

10. As a result of this, we asked health care professionals to speak to their patients who were infected, and families affected to encourage them to come forward.

Recommendations

11. The Chair is asked to make a recommendation that all those affected by thalassaemia, received contaminated blood products and all related infections are offered the following;
    a) access to all their medical records
    b) access to all knowledge of information and treatment options available with regards to their condition
    c) access to emerging and innovate therapies such as gene therapies which would not only improve quality of life but also life expectancy
    d) guaranteed and timely access to liver specialists, pain specialists and rheumatologists for all
    e) guaranteed access to allied health professionals such as dieticians, nutritionists, physical therapies, psychological and social support
    f) guaranteed equality access to dental treatments to all

g) guaranteed access to prescription free medication to all living with thalassaemia

h) to guarantee all health care professionals including medical doctors, nursing teams etc receive mandatory training (and suitably incorporated into medical, nursing and other allied health care curriculums) on thalassaemia, the findings of the infected blood inquiry, risks of blood transfusions, the importance of consent, ethical training, communication skills, patient informed decision making, patient choice.

i) Public funding for the UKTS and other charities who supported and continue to support individuals who were infected or affected to provide advice, education and advocacy services. Public funding would help the UKTS and other charities provide ongoing assistance and campaigning to ensure horrific events like these do not occur.

j) Direct support lines to report any worries or fears of new viruses reported by our members with regards to receiving blood products.

k) A memorial dedicated to all the individuals lost due to this devasting tragedy.

l) A fair compensation package based on the events and diagnoses.

Conclusion

12. In the course of the hearings, it has become apparent that many mistakes were made, and many witnesses have acknowledged that they or the organisations they represented failed in one way or another to meet the standards to be expected of them.

13. When seeking to identify the causes of a major tragedy in which so many people were affected and died, it is important that criticism should be directed at those who truly bear substantial responsibility for what occurred.

14. At this point, UKTS would like to express their profound gratitude to the Chair and all those who worked tirelessly to support the hearings and ensure

they could be conducted as effectively as possible. I have in mind not only our counsel, solicitors, secretariat and support staff.

15. Above all, however, the team at UKTS would like to pay their own respects to the survivors and bereaved.

16. The UKTS team have been greatly impressed by their dignity in the face of the evidence, much of which has been of a distressing nature, and by their fortitude in response to an appalling tragedy.

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