

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional Procedures

Patient Organisation Submission

IP1553 - Patient safety and reduction of risk of transmission of Creutzfeldt–Jakob disease (CJD)

Thank you for agreeing to give us your views on this topic, to help us develop NICE guidance. Patient and carer organisations can provide a unique perspective that is not typically available from other sources. We are interested in hearing about:

- the experience of having CJD, or caring for someone with CJD
- the experience of people knowing they are at increased risk
- any practical impacts on healthcare for those people at increased risk

To help you give your views, we have provided this template. You do not have to answer every question – they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	XXXXXX XXXXX
2. Name of organisation	Child Growth Foundation
3. Job title or position	XXXXXXXXXXXX X XXXXXXX XXXXXXX XXXXXXX
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	Self funding charity with approximately 450 paying members and around 2000 supporters.
5. How did you gather the information about the experiences of patients and carers to help your submission? (For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.) Through informal discussions with members of the Foundation. As a PSG involved in growth, many of our members are prescribed growth hormone and have concerns relating to the potential risks. We have had a small number of members who unfortunately have contracted CJD and passed away.	
Living with CJD	
6. In your experience of working with families affected by CJD, what have they told you it is like to have CJD, and what have carers told you about their experience of caring for someone with CJD? I have only spoken and met directly with one person and she died soon afterwards. It was an extremely difficult time for her mother and son and continued to have an impact over many years.	
Living with knowing you're at increased risk of CJD	
7. From listening to those who have been told they are at increased risk of CJD, but have no symptoms or signs of the disease, what have they told you about what this is like? (For example, impact of mental health, anxiety, impact on daily living) Again, I have only spoken to a small amount of people and the general feeling is that they try to forget about it and do not dwell on the prospect. The feeling is that treatment was successful but it could be a high price to pay, but that is often the case with many diseases	

Impact of being at heightened risk of CJD
8. For individuals at increased risk, what have they told you about any impact this has had on their healthcare (including such things as dentistry) and social care? (For example, any practical implications, discrimination, or other impact on their daily living not covered in Question 7)? I have not had any conversations concerning this
Equality
9. Are there any potential equality issues that should be taken into account when considering this topic? Not to my knowledge
Other issues
10. Are there any other issues that you would like the Committee to consider? No
Key messages
11. In no more than 5 bullet points, please summarise the key messages of your submission. 1. Family 2. Uncertainty 3. 4. 5.

Thank you for your time.

Please return your completed submission to ip@nice.org.uk