

[REDACTED]

[REDACTED]

Mrs Zena Muth
Assistant Secretary to the Inquiry
The Bristol Royal Infirmary Inquiry
2-10 Temple Way
Bristol, BS2 0BY

30 March 2000

Dear Mrs Muth

As the Inquiry considers putting forward recommendations for the National Health Service, we think it appropriate to convey the personal reflections we have on the Inquiry to date and the recommendations we hope it will make related to the experience of the care given to [REDACTED]

Firstly, we wish to express our appreciation to the thanks of the Chairman and Inquiry Panel as expressed in your letter earlier this year. In response, we are very grateful to them, to you, Claire Bache and others within the Inquiry administration for the professionalism, sensitivity and courtesy that has been shown to us over matters which have not been easy for us to consider.

Our personal reflection on the Inquiry related to our personal experience.

The revelations that the Inquiry has brought to light have been leading us to realise that the many problems plaguing the Bristol Royal Infirmary were factors that contributed to the outcome of [REDACTED] second operation.

In this connection we are referring to the problems arising from:

- the apparent conflict between that of clinical interest and that of the child;
- the split site between the Children's Hospital and the Royal Infirmary;
- the problems of inadequate funding and resources;
- the problems of inadequate levels of appropriately qualified staffing and paediatric nursing;
- the problems in the lines of communication especially consultation between senior members of the medical team.

All these factors together give us cause to consider that the outcome of [REDACTED] operation might have been very different if her care had been under another hospital.

Bereavement counselling facilities and the lines of communication at the Infirmary were very poor. It was not evident what the procedures or facilities were in the event of death. In our experience, this sadly resulted in leading us to conclude that the hospital's response to [REDACTED] death was one of overwhelming indifference and insensitivity. The retention of [REDACTED] organs has reinforced this view.

There are many areas of [REDACTED] care that have been a source of grief. Of all these, the retention of [REDACTED] organs has been the one that has upset us the most. It was purely the presumption made by 'professionals' that they could do as they please without any regard to the person of [REDACTED] or consultation with parents. This has shocked us. We acknowledge that pathologists currently are accepting that they were wrong to make such presumptions.

Recommendations we hope the Inquiry will make

Your letter prompts us to consider taking the opportunity of including in this reply a summary of what we hope will be achieved by the Bristol Royal Infirmary Inquiry as a basis for the Government to act upon.

1 Keeping the focus on what is best for children

Our hope for the Inquiry is that it will make such recommendations that will enable medical teams to keep the best interests of the child/patient above clinical interests and to put mechanisms into place to ensure that such focus on patient care is not lost. To achieve this, we would hope that the Inquiry will recommend a Clearing House or some other mechanism so that a child or a patient can be referred to another hospital that has greater expertise and experience to meet the interest of that child if it was felt appropriate.

We hope that the Inquiry will encourage a culture of greater openness and integrity whereby members of medical teams will embrace the processes of evaluation and appraisal of their own performance and welcome the opportunity for retraining or the acquiring of a new skill where appropriate.

We look to the Inquiry to ensure that hospital management teams adopt a cohesive team approach and implement procedures and mechanisms within hospitals that mitigate some of the problems we encountered such as indifference and insensitivity amongst staff. To this end we hope that the Inquiry will ensure that hospital management teams are not plagued by problems of inadequate resources, funding and staffing especially in the area of paediatric nursing as identified at the Bristol Royal Infirmary.

2 Ensuring good lines of communication

We hope that the Inquiry will recommend recognised and formal ways of improving effective and accurate communication within the Health Service:

- ensuring that people concerned fully understand operational procedures and risks involved;
- ensuring that consultation takes place between senior members of the management team and in particular between surgeon and consultant;
- ensuring that people concerned fully understand the forms they sign regarding consent to operations, post mortems and retention of organs;
- ensuring that people concerned are informed about the procedures for complaint and grievance;
- ensuring that people concerned are fully aware of the availability of counselling;
- ensuring that people concerned are informed of the procedures in place in the event of bereavement;
- ensuring that people concerned are aware of the opportunity to return to the hospital to discuss with the medical team the death of a loved one.

3 *A tribute to children*

Finally, we consider it would be a fitting tribute to the children that died at the Bristol Infirmary, if the Inquiry recommended that an appropriate memorial be instituted in the new Children's Hospital currently being built.

We hope that the Inquiry will make such recommendations that will empower medical teams to function at their best and by such empowerment restore the public's confidence in the National Health Service.

Yours sincerely

A large black rectangular redaction box covering the signature area of the letter.

**Response of James D Wisheart to the
Second Review of patient No 05 in the
Clinical Case Note Review.**

There are substantial changes in the second assessment by Team ■ compared to the first assessment by Team ■. The main changes are:

a) Reduction of the following scores:	Overall score	from 2 to 1
	<i>second procedure: ■ 08.93</i>	
	Timing etc of referral	from 4 to 1
	Accuracy etc of diagnosis	from 4 to 2
	Initial strategy	from 4 to 1
	Surgical procedure	from 4 to 2
	Post-op Care 1	from 4 to 2
	Post-op Care 2	from 4 to 2
	Post-op Care 3	from 2/3 to

2

b) Important views are expressed in the following comments:

Additional Comments: *"A very complex and difficult case. Discussion with a group more experienced in the management of this sort of case would have resulted in a more conservative/less ambitious approach to the second operation with a very much higher likelihood of survival"*

Timing etc of referral: *"...reservations concerning appropriateness of referral to this surgical team."*

Accuracy etc of diagnosis:

"Inconsistency in assessment of AV valve incompetence....Right pulmonary venous return not identified."

Initial Strategy etc: *"Better as staged procedure..."*

Surgical procedure: *"Right upper pulmonary veins ligated. Inferior caval conduit inadequate."*

Post-op Care: *"...No evidence of team analysis of what was wrong or steps taken to investigate nature of problem."*

COMMENTS.

The second review raises the following issues:

1. The need for discussion with a more experienced group.

This is a surprising remark in view of the fact that exactly such a discussion did take place.

Dr P Wilde wrote to Prof RH Anderson on the 5th March, 1992 (MR [REDACTED]) and Prof Anderson replied, having discussed the case with his colleagues, on the 2nd April 1992 (MR [REDACTED]).

The discussion with our colleagues at the Royal Brompton Hospital took place because we recognised the unusual nature of the anatomy and sought their advice. Dr Wilde wrote on behalf of the team and stated that surgery was planned. Their reply was helpful, confirming, but adding to, our understanding of the anatomy and outlining a one-stage surgical approach. No question was raised as to by whom, or where, the operation should be carried out.

2. A more conservative approach.

This point is made quite dogmatically both in the Additional Comments, and in the Initial Treatment Strategy sections. The issue of a one stage or a two stage (more conservative) approach was recognised by the team and a lengthy discussion of this point is documented in the following documents: MR [REDACTED]; [REDACTED]; [REDACTED] and [REDACTED].

Following Prof Anderson's letter (MR [REDACTED]) which advocated a one-stage approach, the matter was resolved in that way (MR [REDACTED]).

This issue was not overlooked. It was debated within the team, advice sought from the Royal Brompton Hospital, and in the light of that, a decision was eventually made in favour of the one stage approach. In view of this internal and external discussion it is difficult to

understand how the reviewers can take such a definite stance, while rigorously avoiding the use of hindsight.

3. The surgical procedure.

It is correct that the Right Upper Pulmonary Vein (RUPV) was ligated (Post mortem Report; MR [REDACTED]). This was a technical surgical error.

The RUPV drained anomalously to the Right SVC, but this had not been identified preoperatively. At operation I identified what seemed to be the junction of the RUPV with the atrium (MR [REDACTED]), but in retrospect it cannot have represented **all** of the RUP Venous drainage. I ligated a vein at its junction with the SVC believing it to be the Azygos vein; it must have been **part** of the RUP Venous drainage, as post-mortem showed that the azygos vein had not been ligated.

I can find no evidence to suggest that the IVC pathway was inadequate. It was constructed by using a 'gutter' on the posterior wall of the atrial chamber and roofing it over with a patch of synthetic material, which at post-mortem examination was measured to be 4x3 cms (MR [REDACTED]). Thus the cross-section of the new pathway was made up with the patient's own atrial wall in its posterior portion and roofed over with a synthetic patch in its anterior portion. This pathway was of the order of 2cms or more in diameter, which is generous, and also had growth potential, because it incorporated the patient's own atrial wall.

Could it be that the reviewers have mistaken my hand-drawn diagram, and taken the 3.5 mm to mean the size of the pathway, when it actually referred to the size of the fenestration in the synthetic patch?

4. Post-operative care.

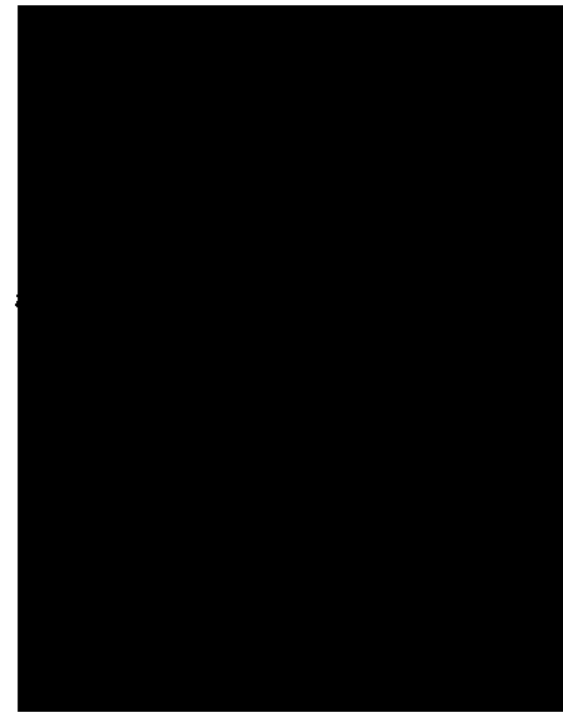
The postoperative medical notes may be seen at MR [REDACTED]. On most days a number of notes were made by the surgical, anaesthetic, nephrology and cardiac radiology teams.

It is correct that there is no note overtly indicating a team discussion; however regular discussions between the surgical and anaesthetic teams would have definitely taken place, as well as a limited amount of discussion with the nephrologists and cardiac radiologists.

While I accept that there is a lack of evidence of team discussion and analysis of the problem, there is no evidence of lack of attentiveness by the surgical team.

Conclusion.

I do accept some of the comments of the second review team, but others seem to be in conflict with the evidence and difficult to substantiate. I would ask the Inquiry panel to give full weight to the points I have made above in considering the surgical aspects of the care of this patient.



RECEIVED
10 APR 2000

Mrs Zena Muth
Assistant Secretary to the Inquiry
The Bristol Royal Infirmary Inquiry
2-10 Temple Way
Bristol, BS2 0BY

7 April 2000

Dear Mrs Muth

Thank you for sending to us a copy of the formal written comments as submitted by Surgeon Mr Wisheart on the second CCNR completed on [REDACTED]

We wish to amplify a fundamental point of principle in the following paragraphs in response to Mr Wisheart's formal comments. The principle we want to amplify is one of the recommendations that we included in our letter of the 30 March, i.e.

We would hope that the Inquiry would recommend a Clearing House or some other mechanism so that a child or a patient can be referred to another hospital that has greater expertise and experience to meet the interest of that child if it was felt appropriate.

Firstly we register Mr Wisheart concedes to a surgical error.

It is correct that the Right Upper Pulmonary Vein (RUPV) was ligated (Post mortem Report) MR [REDACTED]. This was a technical surgical error.

We accept such an error not to have life threatening implications.

Secondly, we agree with Mr Wisheart along with other clinicians to the complexity and difficulty of [REDACTED] case.

Thirdly, we accept the Bristol medical team's recognition of the complexity of [REDACTED] case, and that they sought external opinion by consulting with another hospital, i.e. the Royal Brompton Hospital. We wish to respond to Mr Wisheart's statement: i.e.

The need for discussion with a more experienced group.

The discussion with our colleagues at the Royal Brompton Hospital took place because we recognised the unusual nature of the anatomy and sought their advice. Dr Wilde wrote on behalf of the team and stated that surgery was planned. Their reply was helpful, confirming but adding to, our understanding of the anatomy and outlining a one-stage approach. No question was raised as to by whom, or where, the operation should be carried out.

Our Response

The Bristol medical team sought clarification on the diagnostic complexities of [REDACTED] case. This we understand to have been the purpose and limits of the discussion that took place.

The Bristol medical team did not request a critical appraisal from the Royal Brompton Hospital on their ability to carry out a complex and non-routine procedure on [REDACTED]

The Bristol medical team had not specifically asked for advice from the Royal Brompton Hospital about whether [REDACTED] should be referred to another hospital team.

The Bristol medical team consulted on a basis as to what was the norm at the time.

The Royal Brompton sought to assist the Bristol medical team in clarifying further the diagnosis of [REDACTED] condition and of the surgery planned.

The Royal Brompton Hospital itself was not a Clearing House with powers of referral.

It was not an independent body specially set up to critically examine complex cases with the powers of recommending what was best both in the interests of our child or what was best for the Bristol Hospital medical team to do. We do not think that the Royal Brompton Hospital would consider it in their remit to have done so at the time.

Mr Wisheart and his medical team functioned on the limited facilities open to them at the time. To be fair to the Bristol Medical team and with the benefit of hindsight, such a facility was not available to them whereby such questions could be raised.

The point we wish to make is that the operational procedure for [REDACTED] was not routine. It was unusual and highly complex. The best interests of [REDACTED] needed to be matched with the amount of appropriate experience required for the level of surgery to be performed. It is our understanding from an independent report carried out by Professor Bob Anderson that the Bristol team did not have that matched experience.

When Mr Wisheart began operating on [REDACTED] he encountered further unforeseen difficulties, i.e. the presence of right isomerism and also a leaky atrioventricular valve. Instead of opting for the less ambitious Glenn Shunt operation he continued with the full Fontan procedure. This leads us to consider that the surgical procedure subsequently performed was therefore inappropriate and not correct.

Also the post operative team did not have the matched experience with only one paediatric nurse available for the first night after [REDACTED] operation.

There was no external statutory body which the Bristol medical team was obligated to gain approval from in order to perform such an operational procedure on [REDACTED]

There was no requirement on their part, to demonstrate evidence that they possessed the necessary experience and expertise to match with an operational procedure of such a complex and non routine nature.

There was no clinical advice that the Bristol medical team was obligated to comply with to demonstrate that the best interests of our child was being protected.

Such an external independent body did not exist for the Bristol medical team to apply to.

If such a Clearing House had existed, it could have had powers to refer [REDACTED] to another hospital where the appropriate expertise and experience was demonstrated to be available.

A collective and considered decision would have safeguarded the integrity of the hospital and mitigated the doubts of any impaired judgements being made.

Such a Clearing House (comprised of leading clinical experts) could have assisted the Bristol hospital team in resolving the best course of action for [REDACTED]

It is for this reason we advocate strongly for the recommendation and adoption of some form of **independent** Clearing House to ensure that high quality care for children is secured.

Yours sincerely,

[Redacted signature block]

RESPONSE TO SECOND CCNR: CASE 05 - [REDACTED]

1 A second review of this case was requested by the parents.

2 Although the overall grade of 1 is even worse than the 2 given on the first review, the "principal" reason for this score is the alleged lack of discussion of this "complex and difficult" case with a more experienced group.

2.1 Firstly, this conclusion is wrong. A letter was sent by Dr Peter Wilde to Professor Robert Anderson on [REDACTED] March 1992, asking for advice regarding the details of the anatomic anomalies prior to further surgery. Following discussion with his paediatric cardiology colleagues at the National Heart and Lung Institute, Professor Anderson replied on the [REDACTED] April 1992, suggesting a precise morphological diagnosis and recommending a surgical approach.

2.2 Secondly, although the reviewers state that a "more experienced group" would have recommended a "more conservative/ less ambitious approach to the second operation", ie. a staged procedure, a *total* cavo-pulmonary anastomosis was, in fact, the operation recommended by the *experienced* Brompton group, and carried out by Mr Wisheart. It was during the ensuing years that the staged Fontan procedure became the operation of choice for such complex disorders.

3 The first set of reviewers gave a totally different reason for the low overall score for this case, ie. failure to perform echocardiography post-operatively earlier than day 4. This team actually *commended* the Bristol group for "appropriately" seeking "further opinions" about this "very complex condition".

This case illustrates the propensity for lack of precision and the effect of differences of opinion in the CCNR exercise in some patients, often in those with complex and high risk conditions.

SIGNED

DATE