REQUEST FOR FINANCIAL ASSISTANCE

Contents

- Introduction ................................................................. 2
- Proposed operation ......................................................... 3
- Detailed cost breakdown .................................................... 3
- Finally .............................................................................. 4

Appendix .............................................................................. 5

1. Letter from Prof. Dr. Frank L. Hanley .................................. 5
Introduction

Cara Kibble (born 4.11.1999) has a very rare congenital heart disease called Pulmonary Atresia with Ventricular Septal Defect and Major Aorta Pulmonary Collateral Arteries (MAPCAs). These combined conditions mean that since birth she has had an oxygen deficiency and been unable to participate in normal active child games and sports. As she grows her lungs are getting less and less of the blood they require. Along with narrowing and early calcification of the MAPCAs, Cara’s lung capacity has fallen 30% in the last few years and is deteriorating on an annual basis. The consequences of this are that Cara has a life expectancy of another 8 years, at best. Until recently there was nothing that could be done for this severe, terminal congenital heart abnormality.

However, over the last 5 to 10 years, a very talented doctor at Stanford Hospital in Palo Alto, USA, Dr Frank Hanley, has developed an operation for converting these MAPCAs into a new pulmonary artery – an operation called a unifocalisation procedure - and connecting these to the correct chamber of the heart (the right ventricle). It is complex an open heart surgery, which even after years of development, takes Dr Hanley an average of 12-16 hours. He has performed over 500 of these unifocalisation procedures with a success rate of 98% and patients from around the world with this rare condition are referred to him.

Of the 98% of successful patients, 10% have smaller problems afterwards or do not recover as well as one would have liked, but 88% are healthy and active afterwards. Because he invented this specific procedure that Cara needs, Stanford Hospital have custom built his operating theatre to his specific needs and it is fitted with the most expensive and latest technology available and is staffed with other experts in this and related fields (cardiac surgeons, pediatric cardiac anesthetists and cardiologists). There are only 2 other heart centers in the world that have significant experience with the same procedure, one in Rome with 75 cases and one in Scotland with 20 cases.

Cara had a catheter procedure in September in Stanford to assess her status and viability for the unifocalisation procedure. This indicated that without an intervention she is currently at very high risk from pneumonia, flu, fever and dehydration which might be enough to end her life.
Proposed operation

Dr. Hanley has proposed to perform the major open heart surgery within the next 4 months, due to the above mentioned deterioration of the lung capacity and Cara’s general high risk health condition. He will combine the four or five major collaterals (MAPCAs) that Cara has into one single one (unifocalisation) and insert a shunt to regulate the blood flow into the lungs, as with too much pressure at once it will flood and damage the lungs. After another 6 months of allowing the oxygen to flow into the lungs at a better rate (like giving fertilizer to a plant), a further cardiac catheterisation has to be done to check whether the MAPCAs inside the lungs have grown. If they have, then Dr. Hanley will perform another open heart surgery 2 days later to take the shunt out, close the hole in her heart (ventricular septal defect) she has been living with all her life and insert a donor homograft. Should the MAPCAs not have grown, a catheter will have to be done every 6 months for the next 2 years until there are signs that the MAPCAs have grown and the second surgery can be performed. Should the MAPCAs not respond to the “fertilizer”, the shunt will have to stay in with the VSD open and she will not be completely healthy, but will at least have an oxygen level of over 80%, which is more than she has right now and will allow her to grow into an adult.

This will be a long and grueling time for Cara, extended periods of time away from home, risky open heart surgery, multiple procedures and inevitably periods of pain and fear. However, without taking this chance Cara faces a slow suffocation as her oxygen supply deteriorates.

Detailed cost breakdown

The costs of this procedure and related trips to the US are significant. Dr. Hanley has offered to give his time freely, which is extremely generous and makes a big difference, but still approximately US$1 million (approx. N$7 million) is needed.

We have already identified the following:

- Up to US$42,000 (N$300,000) from medical aid
• US$500,000 (N$3,500,000) has been raised by the family
• We will also approach airlines and others parties involved to possibly grant discounts for the flights and care.

This still leaves approximately US$452,000 (N$3,200,000) to find.

Finally

Cara’s life could be saved by the unifocalisation procedure. Cara’s family and everybody that knows and loves her has been given a glimmer of hope that something can at last be done to save her life.

Healing takes courage, and we all have courage, even if we have to dig a little to find it.
-- Tori Amos

The process will not be without financial and personal cost to the family, but given this chance they need support to try the only thing that might save Cara’s life. Any contributions will help as well as suggestions of where else the family might look for find further support.

Special accounts have been set up to collect the funds for the procedure:

Namibia
Cara Samira Kibble
(Account signatories Kym Kibble & Antje Kesselmann)
Standard Bank
Branch number: 08-23-72
Account number: 04 148 604 8

NB!! Always use reference: KIB3189 when depositing funds

Germany
Mike or Sonja Kibble
Volksbank Raiffeisenbank Penzberg eG., Karlstr.26, 82377 Penzberg
Account Number: 56812
Branch number: 70391800
Bank identifier code (BIC) GENODEF1PZB
Interbank accnr. DE79 7039 1800 0000 0568 12

USA
Sonja and Michael Kibble
Bank of America in Palo Alto, California
account number 0118473241
SWIFT CODE BOFAUS3N
Routing # 026009593

Once the operation on Cara has been performed, the Cara Kibble Medical Account will continue collecting funds to support children with serious congenital heart diseases. Alternatively, should the operation/s and catheter procedures not be performed for whatever reasons, the account guardians will return the unused funds pro rata to the persons or institutions that have donated them.

We thank you for having taken the time to read this and your positive consideration to assist Cara.

Appendix

1. Letter from Prof. Dr. Frank L. Hanley
Mr. and Mrs. Kibble

RE: Carra Klöble  DOB: 11-4-1999

Dear Mr. and Mrs. Kibble,

It was a pleasure meeting with you in August 2010 when you visited Lucile Packard Children’s Hospital to have your daughter Cara undergo an extensive evaluation of her cardiac condition. Her evaluation included an echocardiogram and a cardiac catheterization.

The echocardiogram indicates that Cara has tetralogy of fallot with pulmonary atresia and absent of central pulmonary arteries. Her left and right ventricular function was normal. There is right ventricular hypertrophy. There is the typical VSD of tetralogy of fallot. The aortic, mitral, and tricuspid valves are normal without significant regurgitation.

The cardiac catheterization revealed four collateral vessels. There were two collaterals arising from the left sub-clavian artery. The most lateral of these was the larger of the two. It communicates to the left upper lobe, and has a significant stenosis in its mid portion. Distally it enlarges to approximately 8mm. The pressure, in this blood vessel is 12mm Hg. The second collateral from the left sub-clavian artery arises more proximally and has multiple areas of stenosis before reconstituting to a 5mm lingular vessel. The pressure in this vessel is also low. The third collateral artery arises from the mid descending thoracic aorta; it has a severe proximal stenosis of 2mm and provides branches to the right upper and right middle lobe. The distal pressure in this collateral is 9mm Hg. Each of the main branches of this collateral appears to be approximately 3-4mm in diameter. The fourth collateral artery arises also from the descending thoracic aorta, approximately 1cm below the third collateral. This fourth collateral branches into the left and then into the right lung. The branch to the right lung goes to the right lower lobe. It has a severe obstruction at its takeoff down to 1mm in diameter and then divides into several main branches which are each approximately 4mm in diameter. The distal pressure is 14mm of Hg. The branch of this collateral that goes to the left side is also severely stenotic at its origin; it then branches into two vessels, supplying the anterior and posterior aspects of the left lower lobe. Each of these branches are approximately 4mm in diameter, and the pressure is approximately 14mm Hg.

The catheterization indicates that Cara’s distal vascular bed is well protected with low pulmonary artery pressure throughout. It also appears that most of her pulmonary segments can be accounted for by branches of her collateral vessels.

The concerning aspect of Cara’s collateral anatomy is that the long standing severe stenosis in each of her collaterals has resulted in relatively poor growth of the distal vessels. The left upper lobe collateral vessel which arises from the left sub clavian artery is the only vessel that has relatively normal diameter at 7-8mm. Each of the other distal branches of the remaining collaterals is quite hypoplastic. Other then being somewhat small, all of these vessels look reasonable in their overall contour. I suspect that these vessels do have the potential to grow, quite possibly to normal size, with adequate flow and pressure.
Mr. and Mrs. Kibble
Page two

As you know, my strong preference in patients with this condition is to perform a one stage unifocalization of all of the collateral vessels in combination with a simultaneous intra-cardiac repair. In Cara’s case because of her age, and the long standing severe stenosis that she has in all of her collateral vessels, I am concerned that taking this approach would result in pulmonary hypertension. The pulmonary hypertension would be less a result of problems in her micro-vascular bed, but more a problem of the collateral vessels not currently having the capacity to carry blood flow into her microvascular bed without causing significant resistance. As a result, my recommendation is that Cara should undergo a mid-line sternotomy with unifocalization of all her collateral vessels, with careful assessment in the operating room following the unifocalization to assess the overall resistance in her unifocalized pulmonary vascular system. We can assess this resistance in an objective way with a test that we have developed called the intra-operative flow study. This will give us objective information regarding the resistance in her lungs and more importantly it is highly predictive of what her pulmonary artery pressure would be if we were to proceed with the intra-cardiac repair. If the flow study suggest that the pulmonary artery pressure following intra-cardiac repair would be acceptable, then of course, we would proceed with the intra-cardiac repair following the unifocalization portion of the operation. If on the other hand, the flow study suggested that she would have pulmonary hypertension, then I would not perform the intra-cardiac repair following the unifocalization portion of the procedure. Instead, I would place a shunt from her aorta into the unifocalized pulmonary system to provide flow and pressure that would promote growth of her pulmonary arteries. In most case, in whom we performed shunt procedure the intra-cardiac repair can be performed somewhere in the range of six months to two years following the original unifocalization and shunt placement.

At this time, my best assessment is that it is likely that Cara would not be able to have the intra-cardiac repair at the time of the unifocalization. This is my best “educated guess” based on her age and the size of her collateral vessels. Certainly, if the intra-operative flow study provided objective information that ran counter to my current impression, I would rely on the objective information and proceed with the intra-cardiac repair. I am simply trying to provide you with my best estimate of what is likely to happen. If in fact, it does turn out that the shunt is necessary, I do believe that she has excellent potential to further develop her pulmonary arteries and achieve intra-cardiac repair at a later time.

The typical hospitalization for a procedure that has been proposed above is approximately 10-14 days with approximately 7 of those days in the intensive care unit.

I hope this summary is helpful to you. Please let me know if there is any further information I can provide.

With regards,

[Signature]

Frank L. Hanley M.D.

cc: Johan Brink M.D.
FLH: KM