A story of life before death: Ruth Esther Pana (2nd March 1991- 23rd Feb 2009)

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A week before her 18th birthday Ruth Esther's life came to an untimely end. This was the final chapter of what in many ways had been a remarkable journey.

Help from Mercy Ships

Born in the Cote D'Ivoire on the 2nd March 1991 with a bilateral cleft lip, her father left her mother immediately after seeing such a disfiguring deformity. A few months later the Mercy Ship *Anastasis* arrived in Abidjan and her mother, Bernadette, took her to the screening where she was scheduled for surgery on 19th December by Dr Gary Parker.

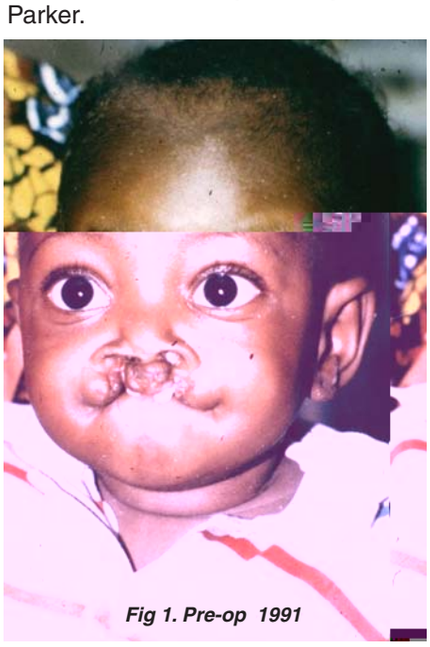

Fig 1. Pre-op 1991

When she arrived on the ship (fig1) routine pre-op physical examination revealed that she was centrally cyanosed (oxygen saturation (SaO_2) on air was only 75%), had clubbed fingers and a pansystolic murmer suggesting a diagnosis of a congenital cyanotic heart disorder. The considerable risks of surgery and anaesthesia were discussed with her 24-year-old mother and the decision was made to proceed. An anaesthetic technique using mainly ketamine was used in an effort to maintain her systemic vascular resistance and hence decrease the risk of an increasing right to left shunt. She survived the surgery during which her SaO_2 ranged between 54 and 75% on 100% O_2. In the post-operative recovery area when she cried her saturation fell to 25%, however when sedated with a low dose subcutaneous morphine infusion the SaO_2 remained in the high seventies. She recovered well and the post- surgical cosmetic result looked good (fig 2).

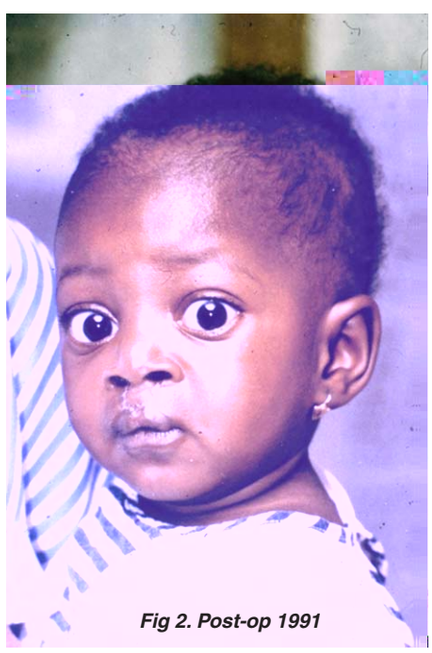

Fig 2. Post-op 1991

Some months later with the help of her pastor, Charles Gbanda, she was assessed by a cardiologist in Abidjan who diagnosed a double outlet right ventricle and a Blalock Taussig shunt was performed. This involved anastamosing the left subclavian artery to a branch of the pulmonary artery to increase the flow of blood through the lungs. The cost of the operation in a hospital in Abidjan was met by my mother, myself and my friend since childhood, Richard Long, who sadly died of a brain tumour in 2006.

Education

At four years old she started kindergarten in Abidjan and the three of us committed to fund her education with the help of Pastor Charles. Over the years his support for the young girl and her mother proved to be unstinting. She went on to primary school from age 6 to 12, secondary school from 12 to 16 and then to another college which she had attended for the past two years during which time she started to

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communicate with me by email in French. Sadly latterly it seems that she had been bullied by some boys because of her slightly scarred upper lip and also because she was unable to participate in physical activities.

Back to the Mercy Ship

In 1998, seven years after her original surgery, I arranged with the Pastor's help to fly Ruth Esther and her mother to Conakry in Guinea for Dr Gary to perform some minor plastic surgery on her lip (fig 3).

Fig 3.

Guinea 1998

During the operation her maximum SaO_2 was 90% definitely higher than in Abidjan. She and her mother stayed with a charming local children's TV presenter called Madame Pouponne, a friend of Mercy Ships.

They returned to Abidjan where Ruth Esther continued her schooling. For about 15 years she came to be one of the patients who represented the 'face of Mercy Ships' with her 'before' and 'after' pictures from 1991 staring out of Mercy Ships literature on both sides of the Atlantic and also used by many speakers including Don Stephens, Lord McColl and myself.

Heart condition worsens

Unfortunately three years ago her exercise tolerance began to deteriorate further; she had to go to school by taxi, a distance which was no more than 20mins walk from home. In December 2007 she had an ECG performed at a hospital in Abidjan but no further action was suggested. I began to consider the possibility of flying her to a European cardiac centre to be assessed by a GUCH (Grown Up Congenital Heart) specialist to see whether corrective surgery might be possible. The first step had been accomplished which was to help both Ruth Esther and her mother obtain Ivoirian passports. Various countries were being considered: the nearest UK consulate was in Accra, Ghana but she did not speak English; France was considered but thought impractical because of bureaucracy and so it seemed that French speaking Switzerland might be the best option.

Visit to the Africa Mercy

In Feb 2009 the newest *Mercy ship* arrived in Cotonou, Benin for a 10 month outreach. Ruth Esther and her mother travelled by bus from Abidjan to Cotonou, a journey which took nearly 36 hours and involved three border crossings. Pastor Gbanda decided to fly by Air Ivoire at his own expense. The Pastor met them at the bus station and drove them to the *Africa Mercy* where they were met by my wife, Fiona and Pierre, a fluent French speaking member of the Swiss Board of Mercy Ships. They were then accompanied on the 20min walk to a nearby hostel which had been recommended by Daslin (former CEO of the *Anastasis* and now married to Pastor Ernest and living in Benin). After walking up only two flights of stairs Ruth Esther was crying with exhaustion and shortness of breath.

Fig 4. Bernadette and Ruth Esther- Feb. 20th

The following afternoon they returned to the ship (fig 4) and were photographed and interviewed with Mercy Ships Founder Don Stephens and myself (fig 5). The next morning Fiona and I, accompanied by her surgeon Dr Gary Parker (fig 6) and his wife Susan took them and Pastor

Fig 5. With Don and Dr Keith

Fig 6. With surgeon Dr Gary Feb.21st

Fig 7. Pastor Charles

Charles (fig 7) for the day to the beautiful Marina hotel and swimming pool complex. We relaxed in the shade of the trees, some of us swam and we ate pancakes. I gave Ruth Esther a present of a digital camera which the pastor managed to set to give instructions in French.

In the evening German anaesthetist Dr Fotios and crew physician Dr Wolfgang assessed Ruth Esther's heart with the ECHO probe of an 80,000 Euro ultrasound machine on loan to Fotios from the manufacturers. It showed that she had a large ventricular septal defect and possible pulmonary hypertension but various anatomical abnormalities made it difficult to interpret.

Images were sent to cardiologists in Germany and in London using a password accessible website. A reply was received from London [1].

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Ruth Esther's last day

On the Sunday morning Fiona and I took them to Mass at the Catholic Cathedral near their hotel (fig 8).

Fig 8.After church Feb. 22nd

The singing by the choir was very uplifting. We then went to a little restaurant for 'croissants and boissons'. They returned to the ship in the evening for supper (fig 9) and attended the evening Communion service before being driven back to their hotel.

Fig 9. With Pierre at supper Feb. 22nd

They both said that they enjoyed the fellowship and the singing. Ruth Esther was able to sing the words in English displayed on a nearby screen.

Apparently that night she talked to her mother until after 1am and among other things told her that she must find somewhere better to live. There is a suggestion that she may have had some kind of premonition. Bernadette also reported a dream about Ruth Esther in which she was crying and saying in French 'let me go', 'let me go'.

The following morning they went to the bus station to purchase their return tickets to Abidjan. Ruth Esther apparently became very angry when they tried to say her student discount card did not count. They then went to the main market to buy a list of things Ruth Esther required for school. While negotiating for a bag Ruth Esther suddenly felt unwell and told her mother to ring Pierre. She then collapsed apparently saying in French 'Jesus come, Jesus come'. A kind Muslim man carried her on a zemidjan (scooter taxi) to their hotel from where they took a taxi to the Port gate to meet Pierre who drove them to the ship. An unconscious Ruth Esther was carried by Dr Fotios up the gangway and then down two decks to the ICU. Her breathing was laboured, she was deeply cyanosed with a base deficit of 23. Her BP was 100/70 and she had a tachycardia of 120. The SaO_2 was very low (about 25%) and CO_2 high. Because she was unconscious she was intubated and ventilated but the SaO_2 only rose to about 45% on 100% O_2 and the high CO_2 persisted. (fig 10)

Fig 10. In ITU Feb. 23rd

She had an A-line and CVP inserted. The diagnosis was uncertain but she had obviously had some event causing increased right to left shunting or perhaps a pulmonary embolus or clotting of her Blalock shunt after the long bus journey. The cause of her collapse was most likely to be cerebral hypoxia. The full medical team involved had a meeting chaired by Dr Gary and it was decided that she would receive full supportive therapy including noradrenaline infusion overnight and then be reassessed in the morning.

Opinions had ranged from stopping all support immediately to redoing her shunt and even to flying her out to a cardiac surgery unit. But all agreed that she should not receive CPR if her heart stopped. Her heart finally gave up the unequal struggle, ignored the noradrenaline and stopped at 2300.

This came as no surprise to anyone except to her poor mum in spite of a discussion with the kindly Dr Gary warning her of the probable outcome.

Post Mortem

The next three days on board the Africa Mercy were spent supporting her devastated mum Bernadette and arranging for the body to be transported back to Abidjan.

Fig 11.Bernadette and Clementine Feb 26th

The former task was done with great kindness and sympathy by fluent French speaking Clementine (fig 11) from Togo, backed up by my wife Fiona, and the latter by the incredibly energetic Pierre. Ruth Esther and her mum Bernadette departed on an Air Senegal flight to Abidjan at 2200 on the 26th Feb only 72 hours after her death. The flight landed on schedule one hour later. A memorial service was held during the community meeting on board the *Africa Mercy* that same evening. I gave a brief powerpoint presentation about her life and Don Stephens read out two emails, one from Pastor Charles [2] and the other from my Sierra Leonean friend Catherine Conteh [3] who had met them in Guinea in 1998. During the showing of a video taken six days before featuring an interview with Don Stephens a collection was taken towards the cost of her coffin and flight back to Abidjan. I found the service very emotional and my tears were never far from the surface.

The Crew on board the *Africa Mercy* were all very supportive of her mother and in a way it was a miracle that she had died on board the ship. The possible alternative of her death during the scheduled return bus

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journey was too unpleasant to contemplate. They probably would have just been thrown off the bus. As a result of a bilateral cleft lip repair as a nine-month-old and subsequent heart surgery, she had enjoyed 18 years of life (fig 12) and impacted many people with her courage – she had had 'life' before 'death' unlike many thousands every year in Africa.

Fig 12.

I will continue to use her photos in presentations I give on behalf of Mercy Ships both as a tribute to the surgical skills of my good friend Dr Gary Parker and also in memory of a very courageous young woman whom it had been a privilege to have helped.

Fig 13. Funeral in Abidjan March 3rd

RIP – Ruth Esther was laid to rest in Abidjan the day after what would have been her 18th birthday (fig 13).

Addenda

[1] *Report from Dr Piers Daubeney, Consultant Paediatric Cardiologist at the Royal Brompton Hospital, London*:

Ruth's clinical details and echo have been passed onto me. She has double outlet right ventricle with either severe pulmonary stenosis or pulmonary atresia hence the original BT shunt. There is a large VSD and LSVC to coronary sinus. The RV is under high pressure due to the VSD. I assume the shunt is now extremely small or even occluded. I doubt that she has pulmonary hypertension unless the original shunt was 5mm or larger (unlikely). If there is a pulmonary stenosis murmur then it implies that she doesn't have atresia but that there is still some forward flow through the pulmonary valve. Her pulmonary blood flow is now critically low. It sounds as if there is shunt thrombosis +/- infected shunt. I would give her heparin or even TPA if there are no other bleeding sites and broad spectrum antibiotics.

She really needs an angiogram into her aorta, right ventricle and both subclavian arteries to visualise her pulmonary blood flow and arteries. She then requires an urgent repeat systemic to pulmonary shunt. If she has a pulmonary stenosis murmur I would try to beta block her e.g. IV esmolol to encourage forward flow through the pulmonary valve and in those circumstances avoid beta agonists.

[2] *Email from Pastor Charles Gbanda in Abidjan*:

Thanks a lot for all you have done for our beloved Ruth Esther for the precious care you gave her from birth to the last breath, May the Lord of grace comfort you, all your efforts are not unavailing it was a major factor to saving a life.

Please convey my condolence to Dr Gary and all the team on the *Africa Mercy*.

[3] *Email from Sierra Leonean Katiemu Conteh in Australia*:

My dear uncle, I am so sorry and sad for what happen it is very hard to understand but we cannot ask God why because he knows more than we do. I just want to say we are with you and Ruth Esther's mum it is our prayer that God will console and restore your happiness again. Uncle I want you to know that she is in a better place with the good Lord and I believe she was happy and appreciated all you did for her on this earth. Therefore, I know she will tell the angels in heaven about your love, care and goodness and will ask them to look over you as you will always live to be her PAPA KEITH.

Stay strong and God bless you,
Katiemu