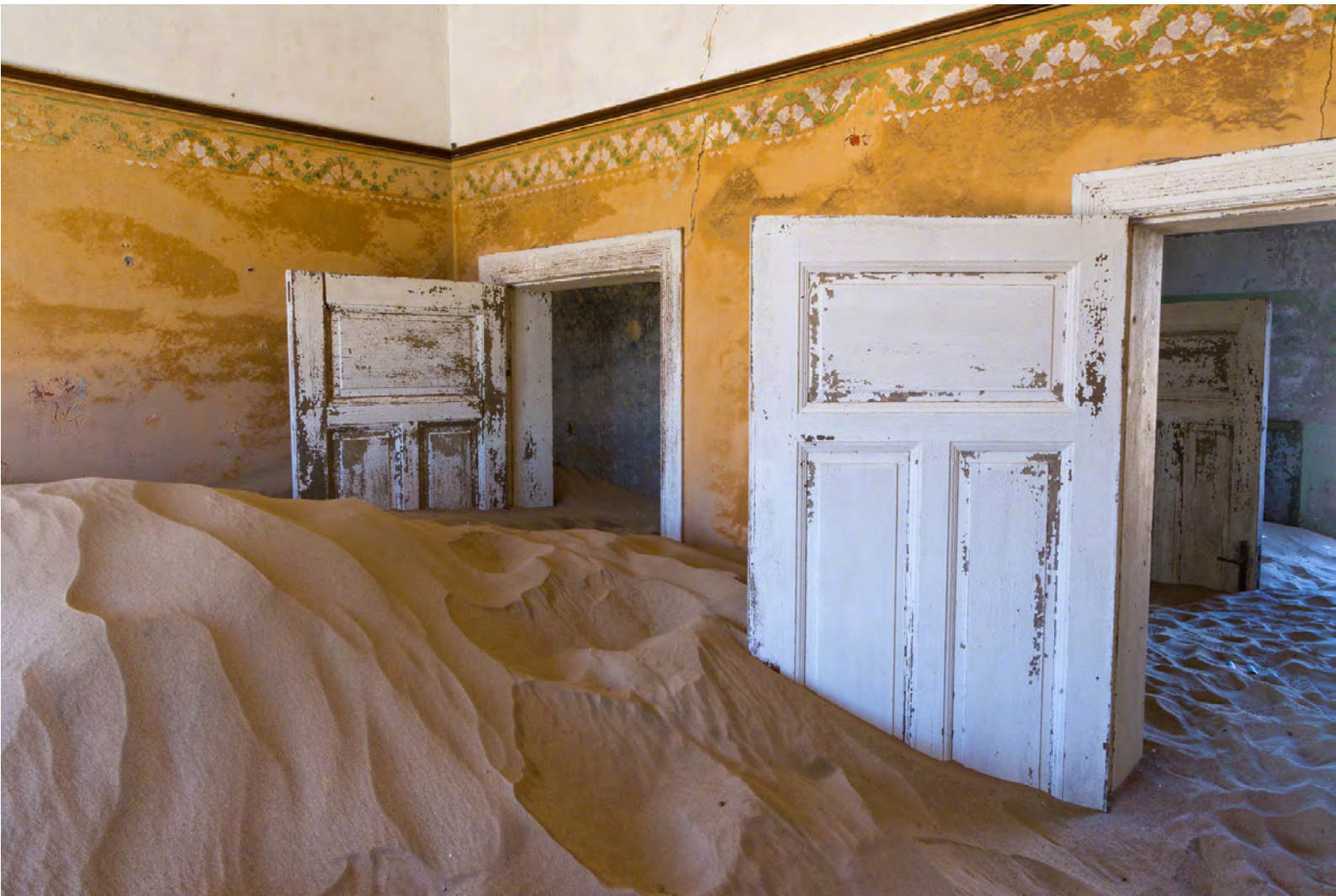
The Royal Children's Hospital Melbourne
50 Flemington Road
Parkville Victoria 3052 Australia
TELEPHONE +61 3 9345 5522
www.rch.org.au

The Royal Children's Hospital Melbourne Alumni

RCH alumni newsletter

November 2017

Kolmanskop in Namibia
Photo by Gigi Williams



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The 2016-7 RCH Alumni Executive

Credits

Editors – Profs. Garry Warne and Jim Wilkinson.

Graphic design – Dan Warne

About the cover photo

Photo by Gigi Williams – Kolmanskop in Namibia. It was a thriving diamond mine in the 1900's and the town was so wealthy that its hospital was the first place in the southern hemisphere to have an x-ray machine. Since it was abandoned for better diamond finds in the 1940's it has been left to be swallowed up by the encroaching dunes of the Namib Desert.

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From the President

The past year has been an active and productive one at several levels.

Membership

22 new members have joined us since the last annual general meeting and after lapses and losses, we now have 171 members, of whom 58 (just over one third) are female. We now have some 27 members (nearly one in six) from allied health, scientific or other professional backgrounds.

During the past year, we were saddened to note the passing of our colleagues Noel Cass, Ric Bouvier, Julie Jones, Don Kinsey and Julian Keogh.

It was great to see that Lyn Gilbert, from our Sydney chapter, was made an Officer in the Order of Australia (AO) for her contributions to infectious disease prevention and control, tertiary education and public health policy.

Events

November 2016 end of year gala dinner at Kew Golf Club

We chose this venue for the second time because of the excellent facilities and organisation provided the previous year. Nearly 80 alumni and guests enjoyed each other's company and an excellent dinner followed by an entertaining and informative presentation by Jim Wilkinson about the Lunar Society of Birmingham, a dinner club and informal learned society of prominent industrialists, natural philosophers and intellectuals, who met regularly between 1765 and 1813 in Jim's home town.

Lunchtime presentations

Once again, we have had several well-attended combined lunch-presentation events, all followed by lively discussion.

In February, in the Ella Latham Auditorium, Gigi & Robin Williams presented a breathtaking visual extravaganza entitled *The Challenges and Rewards of Landscape Photography*.

In April, Jeff Craig from the Murdoch Institute enlightened us about *epigenetics* and its importance in individual and community health.

In June, Mike South described the implementation of the ground-breaking new *Electronic Medical Record* at RCH

In July, our colleague Jim Keipert, a seasoned speaker and prolific essay writer, gave a comprehensive and very well-organised, if somewhat depressing talk entitled *Changes in attitudes and ethical behavior*, examining how a disenfranchised population was leading to a shift to the right in politics

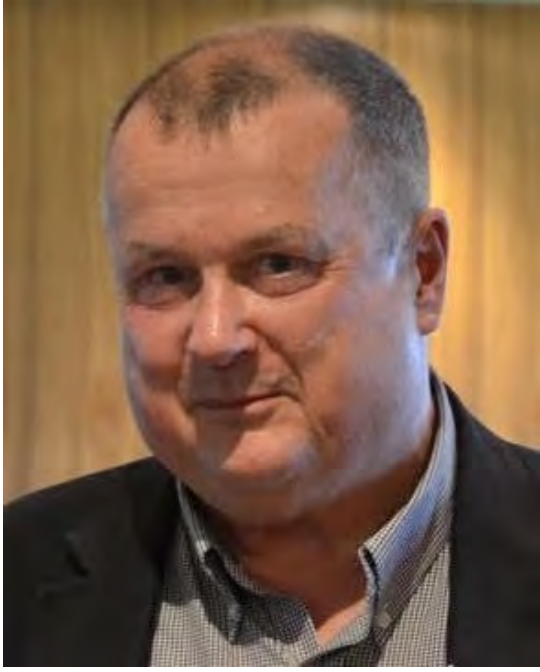
In October, Megan Munsie, our very engaging final speaker for the year, chose the topic *Cashing in on hope: the big business of selling stem cells*.

On April 27 we had a special event, arguably the symbolic and emotional highlight of the alumni year. At the annual Victorian Forensic Paediatric Medical Service (VFPMS) seminar on The Medical Evaluation of Child Abuse, our colleague Bob Birrell was honoured as a visionary and pioneer, whose work 50 years ago formed the basis of an important field of medicine. He was given a special award on behalf of the Royal Children's Hospital, the VFPMS and the RCH Medical Alumni.

We greatly appreciate the support of Anne Smith, Medical Director of the VFPMS, Matt Sabin, Chief of Medicine, and Christine Kilpatrick, former CEO of RCH, in making this possible.

In September, the Vernon Collins Oration, *Improving health in the era of biomedical revolutions*, was delivered by Prof. Shitij Kapur, Dean of the Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne. This was widely acclaimed as an outstanding presentation, both in delivery and content.

Following earlier discussions between Peter McDougall, Executive Director of Medical Services, Trevor Duke, organiser of Grand Rounds, and your president, it had been agreed to trial having the Oration in the lunchtime Grand Round time slot this year, to maximise the attendance of current senior and junior RCH staff. A separate lunch in the Vernon Collins lecture theatre was provided for alumni, members of the hospital board and executive, and the Collins family.



Kevin Collins, President, RCH Alumni
kevincollins.doc@gmail.com

These new arrangements were generally considered a worthwhile improvement. We gratefully acknowledge Peter McDougall's efforts in bringing this about, as well as in securing Prof Kapur as speaker well in advance. While it has been agreed that a similar arrangement will apply for next year's Oration, we await news of the details.

Other RCH relationships

Former nursing staff.

After last year's successful viewing of historical and comedy movies followed by afternoon tea with our former nursing colleagues, it had been planned to run a similar event this year. For various reasons this did not occur, but it is currently planned for February.

Secondly, we understand that the current nurses' organisation may not be meeting the needs of many of its members, given its origins as a league of former nursing trainees from a past era, rather than an association of former RCH nursing staff. Our executive has agreed to meet with theirs to share experiences, in a spirit of helping them to re-organise their own group, if they wish to do so.

RCH executive

Matt Sabin, in his role as Chief of Medicine has kindly offered to be our sponsor within the RCH executive and met with three of us earlier this year to learn how he could help. He has recently reported major progress

in obtaining honorary status for RCH alumni as well as the discounted parking enjoyed by RCH staff. You will be receiving more information about this shortly.

RCH Foundation

Three of our lunchtime presentations this year were held in the RCH Foundation space, which has proved an excellent setting both for lunch and lecture. We are again grateful to the CEO, Sue Hunt, and her staff for making us welcome there.

In February, five of our members represented us at an informal afternoon tea meeting to learn about the Foundation's plans for the future.

RCH Archives and Heritage committee.

We currently have two representatives on this committee, which has been in abeyance since the retirement of the Bronwyn Hewitt, hospital archivist and now our alumni colleague. However, in the lead up to the hospital's 150th anniversary celebration in 2020, we expect to be more actively involved, and have met with the project officer coordinating this.

Alumni web page

Jim Wilkinson continues to maintain and update this most efficiently, with 28 alumni profiles, details of past and future events, recent issues of our newsletter and a photo gallery. We continue to encourage you to submit your own profile.

Alumni executive

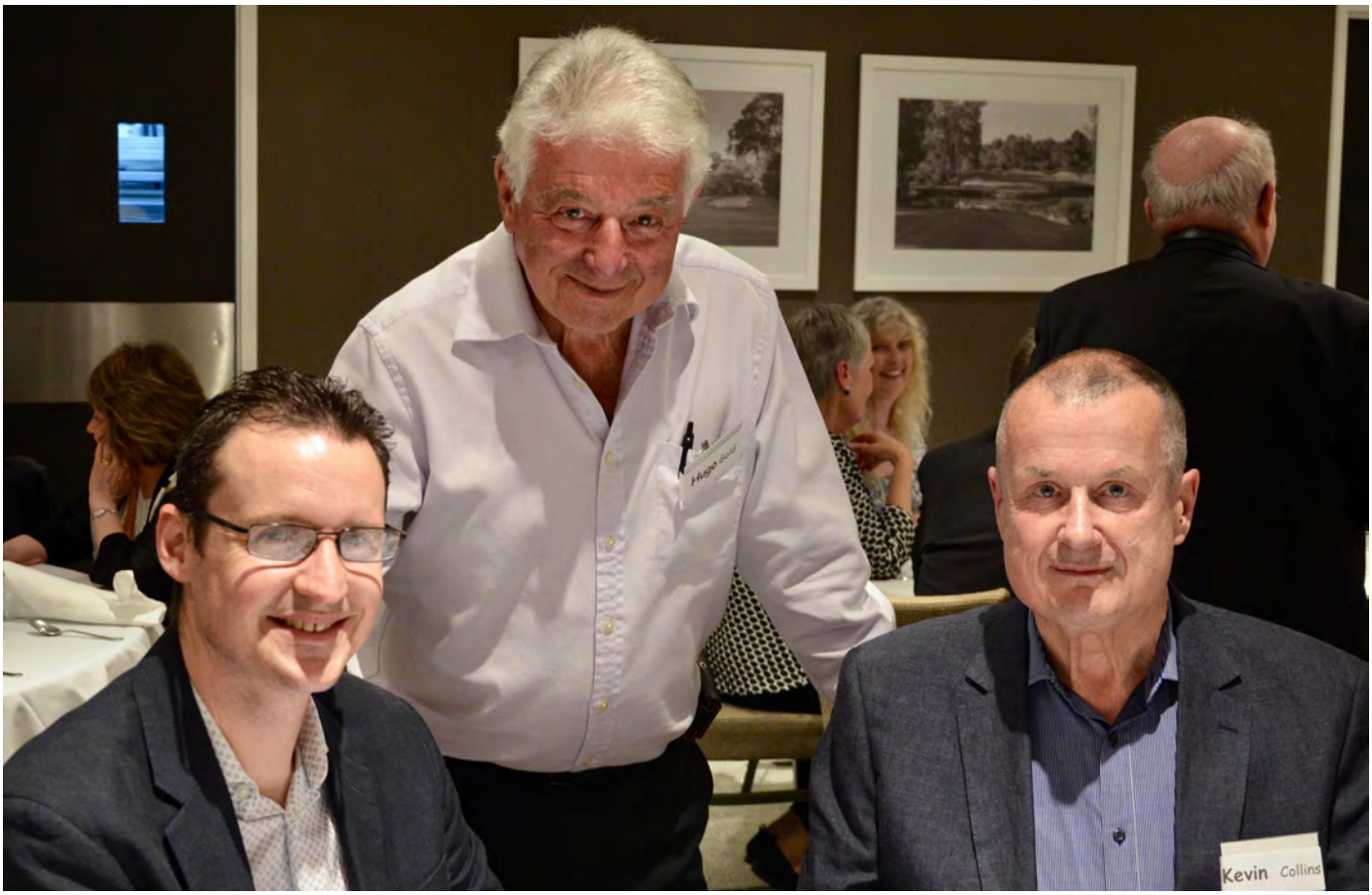
Once again, the number of candidates for election to executive positions exactly matches the number of positions available. I would, however, encourage anyone interested in joining the executive as a future co-opted member to make this known to the incoming team.

At the compulsory end of my two years as president, I want to thank my colleagues on the outgoing executive for another stimulating and enjoyable year.

In particular, Garry Warne has continued to show untiring creative energy and a "can do" attitude where others would have given up. Jim Wilkinson has once again taken care of our finances, our membership database and the alumni webpage in his meticulous yet seemingly effortless way. Karin Tiedemann has willingly and efficiently taken care of catering issues for small and large events, including tonight. Hugo Gold continues to provide succinct but wise guidance as also did Margot Prior before she handed over to Ruth Wraith, who we are very pleased to welcome.

On a personal note, I particularly thank my executive and other alumni colleagues for your encouragement during my seemingly unending but ultimately beneficial six-month medical and surgical odyssey.

Thank you all for your support this year and I wish you good health and happiness in 2018.



Dr Pete Simm, Chairman, Medical Staff association, Dr Hugo Gold, President, RCH Alumni, and Dr Kevin Collins, immediate Past-President, RCH Alumni.

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The Enigmatic RCH Photographer, Jozef Szczepanski[1]

Bronwyn Hewitt

Joe, as he was known at the Royal Children's Hospital (RCH), was born in Dobrzyn, Poland, on 12 December 1912, one of six siblings born to Roman Catholic parents. Joe had completed five years post-primary schooling and two years at University in Poland, studying Philosophy. He was fluent in German, some French and Russian and had 'sound' English skills - enough to pass the Australian literary test. He departed for Australia from an immigration centre in Naples on the ship General Langfitt on 22 May 1949, arriving at Station Pier, Port Melbourne, on 17 June[2]. His immigration record is held at the National Archives of Australia (NAA) in Canberra[3]. He had no relatives in Australia and he didn't marry after his arrival here. Record of his death has not been conclusively found[4].

Szczepanski had served in the armed forces in Poland between 1934 and 1939 where, by the age of 27, he had reached the rank of 2nd Lieutenant when Poland was invaded by Germany in 1939[5]. Then, from September 1939 until the end of WWII, he was interned in Germany in a Prisoner of War (POW) camp, in separate barracks for officers. He had been teaching while he was a university student and again for four years following his release as a POW in 1945. (It is quite possible that he continued to teach during his internment).

Joe had excellent references from the relief organisation for which he was working after the war, as a teacher and occupational trainer. There is one testimonial included in the immigration papers which attests to his good conduct, from 'D. P. Children's Hospital, Schlutup' in Lübeck, Germany, where he had been resident from 16 February 1948[6].

Although Joe's immigration photograph is black & white, we can get an idea of his appearance from his description in the paperwork - 5 feet 4 inches tall (164 cms), 64 kilograms, with blue eyes, fair brown hair and, particularly noted, 'faultless' teeth. He had no history of serious illness, as was the case with the rest of his family.

Having passed the rigorous assessment criteria and various medical examinations required for applicants, and after being declared fit, Joe was selected as a Single Worker under the 'Displaced Persons Resettlement Scheme'[7] on 1 April 1949[8].

Joe was originally employed as a gardener and later as a carpenter at the RCH Orthopaedic Section in Mt Eliza, most likely arranged after his arrival. He was a very creative person and had an interest and talent for photography. There is nothing in his known history to suggest that he had any previous training in photography, but he seems to have had a natural talent for it once he became involved. His style was unique and he had an eye for the unusual. Joe was befriended by, and took many portraits of Lady Elisabeth Murdoch, (later Dame Elisabeth Murdoch and Chair of the RCH Committee of Management).

1 Pronounced Shur-paen-skee

2 The ship 'General Langfitt' was chartered by the International Refugee Organisation (IRO) to transport Displaced Persons to Australia. This voyage was her first such voyage, carrying 826 passengers. The majority were mostly from Europe, Poland and the Baltic countries, in addition to Hungary, Czechoslovakia, Ukraine, and Yugoslavia and were composed of single males, single females, married couples and family groups. (National Archives of Australia, Immigration Department, Series description, A11639).

3 His immigration papers are now on open access at the NAA (Series A11639, Item 4227849).

4 A Stephen Szczepanski is recorded in the Victorian Death Index as having died in Melbourne on 4 Oct 1983. There is no other identifying information on the death certificate, but that person was aged 73, which is very close to the age Joe would have been in 1983. A post mortem was conducted and the man wasn't buried until 11 November, so it can be assumed that he died at his residence and there appears to be no-one who was able to provide any details about him. It is possible that Joe could be this man. It should be noted that the Latin for 'Stephen' is the name from which Szczepanski is derived. More research is required.

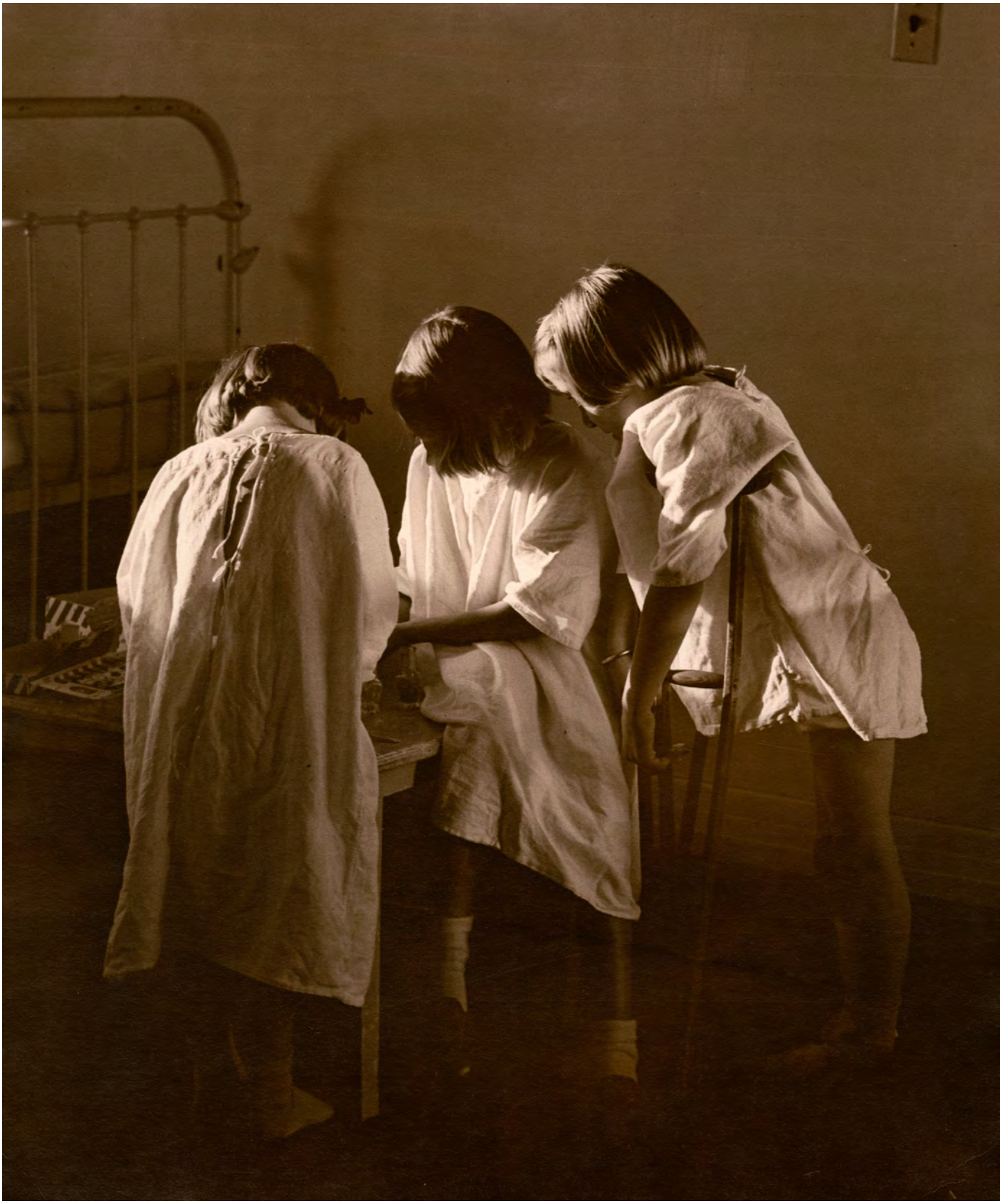
5 'On September 1, 1939, Germany invaded Poland. The Polish army was defeated within weeks of the invasion. After heavy shelling and bombing, Warsaw surrendered to the Germans on September 27, 1939. Britain and France, standing by their guarantee of Poland's border, had declared war on Germany on September 3, 1939'. (Wikipedia).

6 Joe's full employment history is listed in his immigration application papers.

7 'Displaced Persons Scheme - At the end of the Second World War, many hundreds of thousands of people who had been brought to Germany from occupied countries to labour in German industry were unable or unwilling to return to their homelands which were occupied by the army of the USSR (mainly Poland and the Baltic countries - Latvia, Lithuania and Estonia, in addition to Hungary, Czechoslovakia, Ukraine, and Yugoslavia). These people came under the care of the International Refugee Organization (IRO). They were screened, given the status of Displaced Person and housed in camps in Germany, Italy and Austria.

In 1947, the Australian Government agreed to include such people in its migration program under the 'Displaced Persons' Resettlement Scheme'. For a country whose immigration policies had always prioritised people of Anglo-Celtic heritage, it was a significant political shift, which in turn effected a cultural shift'. (National Archives of Australia, Immigration Department, Series description, A11639).

8 It is interesting to note that in his immigration application, Joe stated that he had no money to transfer to Australia.



The RCH asked Joe to be part of the medical photography team in the early days of the first 'Medical Illustration Department', set up independently from Radiology in 1948 under Cyril Murphy as clinical photographer[9]. Joe initially carried out this work at the RCH Orthopaedic Section. His earliest known photographs from this period are dated between 1953-1954[10]. He also took appealing images of patients for the RCH Good Friday Appeal, for RCH publications, (especially Annual Report covers) and collaborated with medical specialists to produce the earliest clinical movie films at the hospital[11]. When the RCH Orthopaedic Section closed in 1971 and the remaining patients were transferred to the RCH Parkville site, Joe continued his work as a medical photographer there.

At the inaugural Victorian meeting of the Australian Medical Photographers & Illustrators held at the RCH in 1974, Joe was one of a small group of medical photographers responsible for mounting an exhibition for the 70 participants who attended. Following the success of this meeting, in Adelaide in 1976, a new national body was formed – the 'Australian Institute of Medical & Biological Illustration' (AIMBI)[12].

Several of his former colleagues remember Joe's great interest in the Polish astronomer and mathematician, Nicolaus Copernicus (1473-1543). They especially remember a fascinating and dramatic lecture and slide show, set to music, which he delivered at the RCH on the life of Copernicus. Another of his interests was to make a vodka-based drink using fruits and plants[13] which he would share with his friends and colleagues. He was also fond of touring Australia in his old Volkswagen Beetle; he was a member of an early Polish Club in Melbourne.

Joe was also a member of the Melbourne Camera Club between 1954-1960[14]. The Club holds in their permanent collection, two of his black and white images dating from 1958 & 1960, after which time he appears to have not renewed his membership. He was technically highly competent and his acceptance in exhibitions and salons[15] indicates that his artistic work was of a high standard[16]. He was highly regarded in the Melbourne Camera Club and is universally admired as a photographer. Everyone who knew Joe speaks fondly of him as 'a lovely man'.

Jozef Szczepanski was a sensitive and talented photographer whose work not only served an important clinical role at a time when the profession was developing, but also added dimension to the public perception of the RCH, communicated through his artistic portrayal of young patients. This made his work accessible and able to be appreciated by a wider audience which remains the case today. Joe richly deserves recognition for his work and his place in history.

9 Peter Yule, *The Royal Children's Hospital, A history of Faith, Science and Love*, Halstead Press, 1999, p. 547

10 Collected in albums held in the RCH Archives. All images are B&W.

11 These films are held in the RCH collection.

12 'AIMBI was founded in 1976 to bring together illustrators from the fields of medicine, science, photography, industry, teaching, television and cinematography'. (AIMBI website).

13 This may have been based on a traditional Polish blend.

14 Alan Elliott, Archivist, Melbourne Camera Club.

15 The RCH Archives holds a collection of large format, mounted B&W prints that Joe entered in exhibitions at the Melbourne Camera Club and the Singapore Salon during this period. One of these has been hand coloured.

16 Joe used a professional model 'Plaubel Makina' camera that took 6 X 9 cm images on 120-size roll film. (Alan Elliott, Archivist, Melbourne Camera Club).

Jozef Szczepanski at work in the early 1970s. Photo courtesy Adrian Daniel.

Inaugural meeting of Australian Medical Photographers & Illustrators held at the RCH, 1974. L-R: Medical photographers Adrian Daniel, (RCH) John Scrimgeour, (Eye & Ear Hospital), Joe Szczepanski (RCH) and Arthur Wigley, (Royal Melbourne Hospital). Photo courtesy Adrian Daniel.

Sources

- National Archives of Australia (NAA), Department of Immigration, Ref. Series A11639, Item 4227849
- Victorian Registry of Births Deaths & Marriages, index reference No. 25445/83.
- AIMBI website - https://aimbi.org.au/
- Wikipedia - https://www.ushmm.org/wlc/en/article.php?ModuleId=10005070
- Peter Yule – 'The Royal Children's Hospital, A history of Faith, Science and Love'. Pub: Halstead Press, 1999.
- T C Kester Brown, former Director, RCH Department of Anaesthesia (1974-2000)
- Adrian Daniel, former HOD, RCH Department of Medical Illustration (1965-1974)
- Roger Hall OAM, former RCH Director/Associate Professor of Dentistry (1960-1998)
- Bronwyn Hewitt, former RCH Archivist (1991-2017)
- Alan Elliott, Archivist, Melbourne Camera Club

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Calming the Distressed Child – A Pilot Study

Geoff Mullins

Abstract

Objective: To evaluate the calming effect of suspending distressed children upside down.

Design, setting and participants: A prospective study in the community of three healthy children.

Intervention: Children exhibiting distress were suspended upside down.

Main outcome measures: Absence of vocalization, altered facial expression and absence of gross motor movement.

Results: In the ten episodes of distress studied all resulted in almost immediate calming with silence, absence of gross motor movement and depending on the age of the child a bemused or smiling facial expression. In one episode a child attempted to bite the operator before becoming calm.

Conclusions: In this pilot study suspending healthy distressed children upside down had a rapid calming effect on the child. The findings have implications for both clinical and non-clinical practice. Further studies are necessary before the technique can be used in a clinical setting

Introduction

Short episodes of distress in healthy infants and children are common and are particularly common in the medical setting when examination, investigation and treatment procedures are required. Once distress occurs calming the infant or child is difficult and often unsuccessful. This is particularly seen prior to induction of anaesthesia where up to 40% of young children may become distressed[1] complicating and delaying optimal care of the child. Many techniques in both the medical and non-medical setting are used in attempts to calm distressed infants. No single technique has been shown to have a high success rate particularly once distress has occurred. A chance observation demonstrating that distressed piglets when held upside down quietened immediately (ref. 2) led to a trial of this technique in children exhibiting signs of distress.

Method

Three healthy children aged 18 months, 3 years and 6 years respectively were selected for the trial. Informed consent was obtained from both parents and they were tutored on the technique to be used.

The children were monitored for signs of distressing behavior unrelated to pain. This was identified as screaming or crying and unfocused gross motor activity. The parents were instructed to attempt to comfort and reassure the child but not to use bribery or bargaining techniques.

Once it was established that the distress was not responding to comfort and reassurance, one of the parents (the operator) was instructed to promptly grasp the child by both ankles and suspend the child upside down whilst the investigator (the author) monitored the effect on the child's distress.

Results

Over a two-week period ten episodes of distress unrelieved by comfort and reassurance were identified in the study participants. Episodes were most frequently precipitated by events such as unmet requests for confectionary items or toys, sibling rivalry or requests to cooperate with bathing or retirement to bed of an evening. Of the ten episodes four were with the 18 month old, four with the three year old and two with the 6 year old. In all episodes crying, screaming and struggling ceased almost immediately the child was turned upside down. There were some differences noted in other responses that appeared age related particularly in facial expression. The 18 month old adopted a calm but rather bemused demeanor. The three year old smiled broadly and appeared to enjoy the experience. The six year old, although initially apprehensive and voicing concerns about being dropped on the floor, quickly calmed, relaxed and appeared also to enjoy the experience. The only untoward effect occurred with the three year old during the first occasion of being turned upside down. This child initially attempted to bite the operator just prior to smiling and becoming calm.

Discussion

Distress in infants and young children as manifest by crying, screaming and uncooperative behaviour is not an uncommon event and can be both distressing for parents, medical attendants and spectators to witness and or manage. It is unfortunately all too common in the medical setting when examination, investigation and treatment procedures are required. This behavior is particularly common prior to induction of anaesthesia in infants and young children. Despite much investigation and research, prediction of this behavior prior to induction of anaesthesia has proven to be difficult and preventative strategies have met with limited success. These strategies have included behavioral preparation programs, play therapists, clown doctors, hypnosis, preoperative sedation and parental presence at induction. Once the distress occurs management options are limited beyond comforting, reassurance and reasoning. Physical restraint invariably increases the distress and is distressing for attendants, parents and onlookers. Cancellation of the procedure and rapid removal from the offending environment whilst often successful is often impractical. Likewise in the non medical setting acquiescing to the often unreasonable demands of the child whist successful in the short term may lead to undesirable consequences in the long term.

This pilot study was precipitated by an observation of the behaviour of piglets in a surgical research study[2]. When the piglets in this study were presented for anaesthesia they commonly squealed, squirmed and appeared distressed. On holding them by their hind legs and suspending them upside

1 R J Holm-Knudsen, J B Carlin, I M McKenzie. *Distress at induction of anaesthesia in children. A survey of incidence, associated factors and recovery characteristics*. Paediatric Anaesthesia 1998; 8: 383-392.

2 Geoffrey C Mullins. *Pigs, burns and curly tails.* Med J Aus. 2008; 189 (11/12): 666667

down they immediately calmed and accepted the facemask for induction of anaesthesia calmly.

On using this technique in three healthy children aged, one, three and six years during ten episodes of distressing behavior all children rapidly calmed, adopted either a bemused or smiling countenance and ceased gross motor activity. There was only one episode of an untoward response to the technique. The three year old child in the first of her four episodes initially attempted to bite the operator prior to becoming calm. This child however has a past history of biting and a family history of biting in early childhood which has usually subsided by 4 years of age.

A possible confounding issue in this study was that in many of the episodes the children not only became calm but also smiled and appeared to be enjoying the process thus raising the possibility that children once managed by this technique may feign distress to obtain an up side down experience. Whilst this pilot study yielded excellent results – 100% success rate in relieving distress in healthy children - there are some safety concerns with the technique. To hold a child securely upside down by the ankles requires a degree of strength and confidence on the part of the operator. The technique should preferably be undertaken over a soft surface or bed and unless the operator is willing to undertake strength training exercises or there are two operators involved, the technique should be limited to children of 15 kg or less. The six year old child in this study weighed 21kg and the parent (operator) is a weight lifter.

In conclusion this pilot study demonstrated that holding a healthy distressed child upside down by the ankles has an immediate calming effect leading to either bemusement or obvious enjoyment. The results of this pilot study involving three children in ten episodes of distressing behaviour are very encouraging, however further more rigorous investigation in a larger population of children is warranted and required to confirm these results and the safety of the technique.

Disclaimer

None of my grandchildren were harmed in the conduct of this study.

Editorial

A W Duncan
Retired Editor

In this issue of the RCH Alumni Newsletter, Mullins reports the findings of a pilot study describing the calming effect of suspending distressed children upside down. Whilst the author deserves commendation for exploring ways to deal with this challenging situation, the study has some limitations.

The report does not mention approval from a properly constituted HREC. There is no indication whether written informed consent was obtained from the parents, and there is no mention of informed consent (written or verbal) from the subjects or that subject consent had been waived because of the circumstances.

The study is purely observational in nature without audio or video recording to confirm the claimed benefit. The sample size is extremely small and there is no control group. What is the effect on the same cohort when not distressed or a group of age matched controls when held upside down? There is little detail about the subjects other than age. For example, what was their sex and were any of them redheads like the author? There is no mention of long term follow up to demonstrate either improved behaviour or psychological scarring.

Only one possible confounding variable is mentioned; is it possible that the non involved parent or grandparent used other means of coercion such as threats or lollies?

The pilot study was based on a chance observation demonstrating a calming effect when piglets are held upside down[1]. That report involved only 10 piglets, one of which developed a short episode of profound hypoxaemia and a postoperative cerebral "grunt". It is pleasing to note that no such complications were observed in these children. Finally, Mullins should be aware of the risks of extrapolating from animal studies (albeit an animal with some similar behavioural characteristics) to emerging humans.

Conflict of Interest

I need to declare that I am a close personal friend of Dr Mullins and this editorial may have been more favourable than was deserved.

1 Mullins G C. Pigs, burns and curly tails. Med J Aust 2008;189(11):666-667

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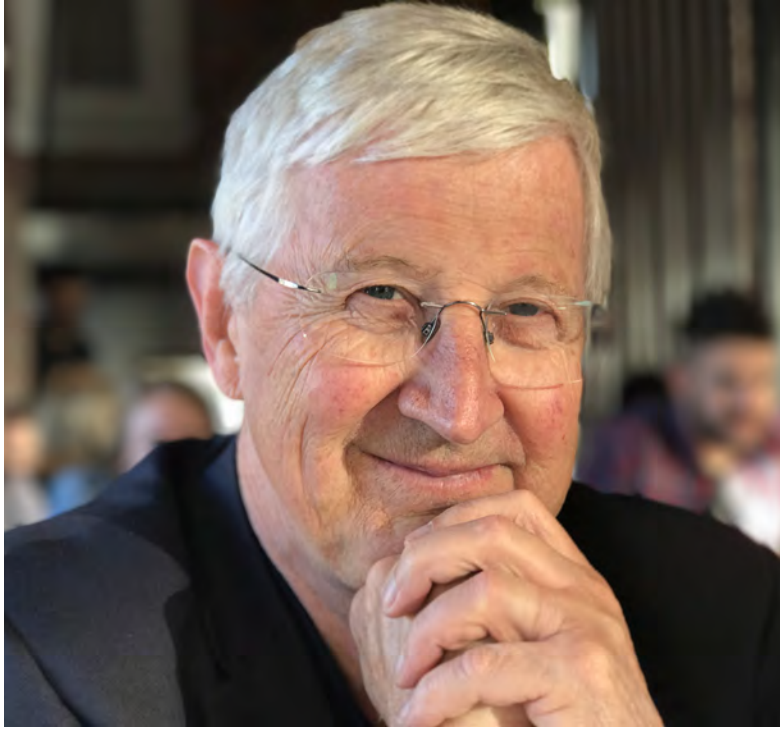
How not to deal with complaints

Garry Warne



A housewife and mother of two, Prita Mulyasari, was admitted to the Omni International Hospital in the Indonesian city of Tangerang with a fever. She had a bad experience involving a dispute with staff about the validity of test results. This was not resolved satisfactorily through discussion and she signed herself out. On reaching home, in a very distressed state, she sent an email to several of her relatives and friends, telling them what had happened to her and warning them to be wary of the hospital. The content of the email spread through mailing lists and internet sites and before long, found its way back to the hospital administration.

In Australia, this would probably have been ignored, or perhaps the hospital would have asked its public relations department to contact the patient, express regret for what had happened, inform her that an investigation into the matter would be carried out immediately and that if the hospital was at fault, efforts would be made to correct the system so that the same thing would not happen to another person. Feedback would always be sent to the complainant about the outcome of the investigation and the action taken, if any. If the hospital had been at fault and if, as a result, the patient had suffered injury or any form of harm, compensation would be negotiated. The hospital would make every effort to keep the matter out of the hands of lawyers and definitely try to keep it out of court and the newspapers. But that is not what happened in Indonesia!

The hospital reacted with maximum force and brought criminal libel charges against the woman, demanding a 6-month jail sentence. Not satisfied with that, they went further and brought civil charges against the woman. She was fined 204 million Rupiah (US$ 22,863) by the Banten High Court and detained. She was subsequently acquitted of the criminal charge in the district court, and lodged an appeal against the civil charge in the Supreme Court. This was opposed by the prosecutors, who demanded that the penalty be increased to 2 billion Rupiah on appeal. Prita won the appeal, however, and the prosecutors' demands were struck down.

The Indonesian people were appalled at what they perceived to be a flagrant abuse of the judicial system and an injustice against a citizen. There was a public outcry and the story became headline news in the Jakarta Post (http://www.thejakartapost.com/ news/2010/10/09/top-court-favors-prita-over-omni.html). Community organizations rallied support from their members through internet social networking sites and a nationwide 'Coins for Prita' appeal captured the hearts of rich and poor alike. Beggars donated their meagre takings, wealthy people gave generously and Rp 615 562 043 (US$ 65 249) in coins ended up in a very large heap on the living room floor of one of the organizers. Bank Indonesia counted the money without charge. Lawyers donated their services and were successful in having Prita released from prison and in having the appeal to the Supreme Court denied. The embarrassed hospital administration relented and withdrew its demand for the fine to be paid. The woman, out of prison and celebrated as a national hero, then found the ultimate inspiration and donated the collected funds to a not-for-profit organization that fights for people suffering injustice.

This story of how not to deal with complaints is shocking because it actually happened. We might wonder how the administrators of the hospital could have been so short-sighted and vindictive. Presumably they had reason to be confident that the judicial system would support them and they hoped to make an example of the woman, so that others who might be planning to complain or make trouble for them would think twice about it. But clearly, they lost perspective and failed to see the possibility of political consequences from this course of action, because under a previous government, political demonstrations had always been severely dealt with in Indonesia.

Hospitals exist for the patients, not for the administration or the staff. Family and patient-centred care should be a right, not a privilege. Family-centred care requires that families become central to the delivery of healthcare. It involves creating equal partnerships with families and collaborating with them at all stages of healthcare—planning, delivery, evaluation of healthcare and in education of healthcare professionals. Family-centred care should become the norm across the healthcare system. Family- centred care is a fundamental shift in the distribution of power to give patients and their families an active voice in their healthcare. Family-centred approaches lead to better health outcomes, improved quality and safety, wiser allocation of resources as well as greater patient, family and staff satisfaction.

These collaborative relationships are guided by the following principles: respecting each patient and family, honouring racial, ethnic, cultural and socioeconomic diversity and its effect on the family's experience and perception of care; recognizing and building on the strengths of each patient and family, even in difficult and challenging situations; supporting and facilitating choice about approaches to care and support; ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each patient and family; sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming; providing and/or ensuring formal and informal support; and empowering each family to discover their own strengths, build confidence, and make choices and decisions about their health.

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When best interests are not good enough

Hugo Gold

The tragic and now notorious case of the infant Charlie Gard illustrates the limitations of using the 'best interests test' as the sole or major determinant in reaching decisions in cases when doctors and parents disagree about treatment.

Generally, the test of best interest serves clinical decision making very well, accounting as it does for a balanced assessment of harms and benefits.

However, assigning value to benefits, risks and harms often involves judgements about issues such as suffering, quality of life, the significance of disability and the sanctity or "infinite value" of life. If, for whatever reason, these values are not shared, reasonable people can come to different views about what is in the child's best interests.[1,2]

The problem posed by the best interest standard is that it does not easily allow for anything less. Accepting a "second best" or good enough outcome can become very difficult for both sides in a dispute.

When agreement cannot be reached, moral distress, anxiety and confusion for all parties arises. Resort to the law with its customary adversarial perspective often makes things worse. The therapeutic alliance is put at risk, trust may be lost, and the inevitable delays result in a sense of missed opportunity and moral regret. Such appears to have occurred in the case of Charlie Gard.

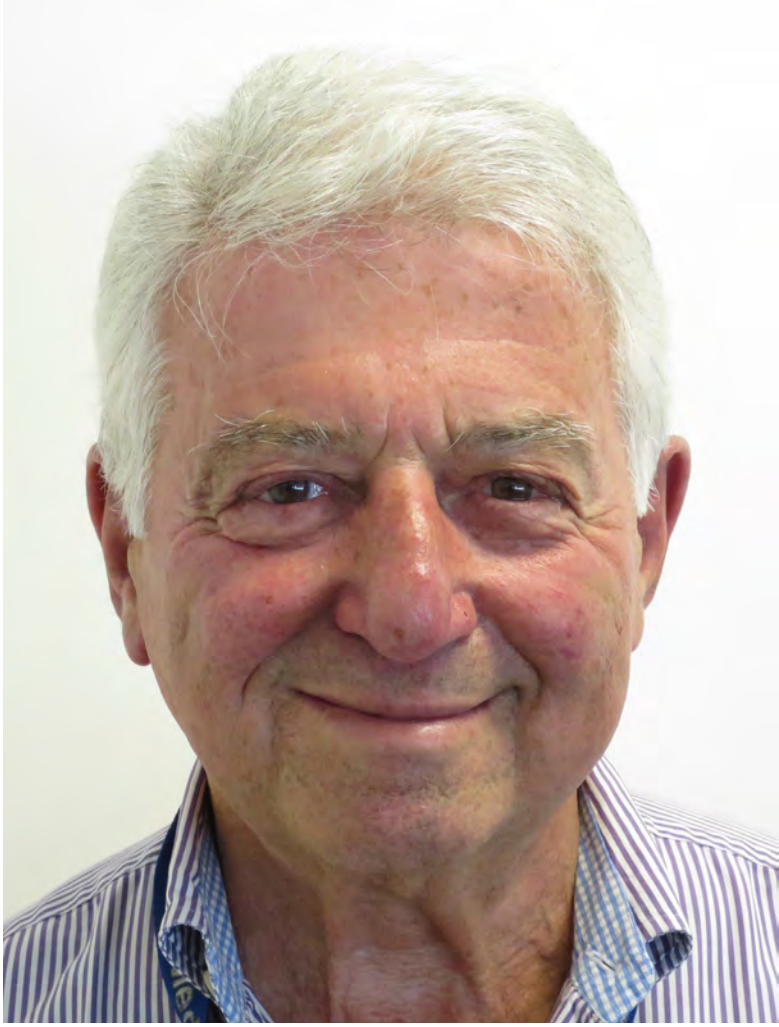
Charlie Gard was born with an extremely rare, genetically determined mitochondrial DNA depletion syndrome which results in progressive muscle weakness and brain damage. There is no established cure, and life expectancy is between 3 months and 12 years from the time of diagnosis. Treatment is usually symptomatic and ultimately palliative, and this was what Charlie's Great Ormond Street Hospital (GOSH) doctors advised.

Charlie's parents had requested the addition of a novel therapy which uses a nucleoside. This request appears to have been considered by his GOSH doctors. However, whilst awaiting legal and ethical approval, Charlie's condition deteriorated to the point that brain damage became so profound that his doctors felt that no feasible benefit could result from this treatment. They informed Charlie's parents that it was now time to move to palliative care.

The parents disagreed, based on an indication of a slim possibility of benefit from a Columbia University neurologist who had experience of treating 18 patients with similar but genetically different conditions in Spain and Italy. Charlie's parents then arranged to take Charlie to the USA for treatment. The necessary immigration permission was obtained. The hospital then applied to the family division of the UK high court to prevent Charlie's removal. Amidst great public interest both the Pope and Donald Trump offered to help him get treatment, in Rome and the USA respectively.

1 Savulescu J. Is it in Charlie Gard's best interest to die?. The Lancet. 2017; 389(10082):1868-9.

2 Wilkinson D. Beyond resources: denying parental requests for futile treatment. The Lancet. 2017; 389(10082):1866-7.



Parents have the right and duty to make medical (and other) decisions for their children. However, their decisions may be challenged or limited on the basis of a "best interest" threshold, particularly in the UK. Indeed, in Charlie Gard's case, Mr Justice Francis made formal declarations that "it was in Charlie's best interests" not to undergo treatment in the USA, not "in his best interest" for artificial ventilation and hydration to continue, and on the contrary, "it was in his best interest" for it to be withdrawn[3].

In judging treatment not to be in Charlie's best interest, the GOSH doctors, supported by the court, were influenced by the suffering caused by continuing mechanical ventilation, likely to be increased during the proposed transfer. In April the high court judge ruled that it was in Charlie's best interest for mechanical ventilation to be withdrawn, for palliative care only to be given and for Charlie not to be given nucleoside treatment. The parents appealed the judgement which was ultimately upheld both in the UK courts and the European court of human rights.[4,5]In all, these proceedings took several months. The financial costs (even with pro bono help for the parents) must have been considerable, and the emotional costs to all concerned can only be imagined.

The hope for a "miracle cure" and the request for novel treatments, often "discovered" via an internet or social media search, is a natural and common parental response

3 Great Ormond Street Hospital v Yates & Gard [2017] EWHC 972 (Fam) (11 April 2017). Available from: https://www.judiciary.gov.uk/wp-content/uploads/2017/05/gosh-v-yates-and-gard-20170411-1.pdf. Accessed 31 August 2017.

4 Great Ormond Street Hospital v Yates & Gard [2017] EWHC 1909 (Fam) (24 July 2017) Available from: https://www.judiciary.gov.uk/wp-content/uploads/2017/07/gosh-v-gard-24072017.pdf. Accessed 31 August 2017.

5 Gard and Others v the United Kingdom (European Court of Human Rights). (3 July 2017). Available from: http://hudoc.echr.coe.int/eng?i=001-175359. Accessed 31 August 2017.

to situations such as Charlie's. As stated earlier, when there is uncertainty about efficacy, and particularly when values are not shared, establishing "best interests" can be difficult, confusing and the cause of much moral distress.

It is possible, however, that approaching the problem from a different standpoint could avoid much of the moral distress and confusion and allow for the development of an approach acceptable to all. When doctors' and parents' views about management cannot be reconciled, applying the principles of the Zone of Parental Discretion (ZPD)[6,7]could allow for a mutually acceptable way forward.

The essential idea of the ZPD is to replace the need for a best interest outcome with one that is good enough to be acceptable to all. It seeks compliance with the parents' wishes, and an understanding of their goals of treatment, but is limited by the extent of probable harms.

In accordance with these principles, the response to the parents' request for the novel nucleoside therapy would be to conditionally agree. This would remove a major source of conflict by agreeing that a trial of nucleoside therapy with the aim of curing or mitigating the condition was one of the goals of treatment. The central questions would then become "What would happen to Charlie if his parents' wishes were followed? How bad would it be for him?"

The principal reason for refusing or discontinuing treatment rests on that treatment resulting in unacceptable harm in the form of increased pain or discomfort, or additional damage. Charlie's condition was so bad, and his prognosis so poor that it seems unlikely that nucleoside treatment could make it worse. It would therefore be within the ZPD.

The proposed transfer of Charlie to the USA, if it indeed was necessary, would likely cause additional pain and discomfort. This increased probability of harm may take it beyond the ZPD.

There are other relevant ethical concerns involved in considering novel treatments such as Charlie's proposed nucleoside therapy. These are not directly addressed by the ZPD principles, but underlie the conditions required to allow treatment to proceed.

Firstly, there must be a plausible or feasible rationale for the proposed treatment. Whilst assessing the evidence for the proposed nucleoside therapy is beyond the scope of this paper, it seems possibly sufficient to allow for a trial of treatment.

Secondly, it is important to recognise that the therapy is a trial. Clearly defined indicators of response and timelines need to be set, with a clear understanding that failure to respond signals cessation of this therapy.

Thirdly, the issues of equity and distributive justice may require that the cost of Charlie's novel treatment be met from non-hospital private sources. This would aim to provide for the costs directly added by proceeding with novel treatment. There should be sufficient resources to ensure that no other patients are deprived of conventional treatment, such as the availability of an ICU bed. The parents appear to have raised sufficient funds (almost $2 million) to meet these needs, with the potential to raise further funds if required.

Therefore, at least on the assumptions above (especially if transfer to the USA was not required), it appears that each of these conditions could be satisfied. A time limited trial of treatment in accordance with the parents' request might have avoided conflict, preserved the therapeutic alliance and built trust. Moral distress might have been minimised, and the resort to the courts have been unnecessary. Under these circumstances an appropriate transfer to palliative care might have been accepted as one of the agreed goals of treatment.

A significant advantage of applying the ZPD approach is that it does not depend on a reconciliation of divergent religious, philosophical or moral beliefs about things like the meaning of suffering or the infinite value or sanctity of life. It respects the divergent views but is not dependent on them and it maintains the primary role of the parents. Conflict resolution is achieved by an acceptance of what is "good enough" rather than what is "perfect" – the best need not be the enemy of the good.

6 Gillam L. The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. Clin Ethics 2016;11:1-8. Link: http://journals.sagepub.com/doi/pdf/10.1177/1477750915622033 (accessed 30.8.17).

7 McDougall R, Delany C, Gillam L, editors. When Doctors and Parents Disagree: Ethics, Paediatrics & the Zone of Parental Discretion. Sydney (AU): The Federation Press; 2016

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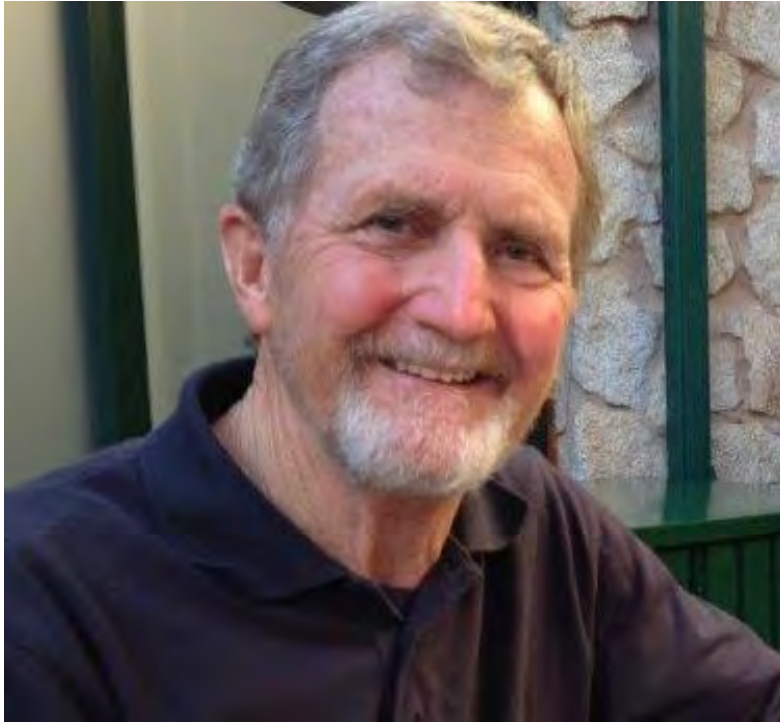
The Kiss

A tale of anxiety, innocence and trust in the anaesthetic room

Geoff Mullins



As I entered the busy paediatric ward, I scanned the room for my patient- they're often not easy to find among the children, the visiting parents and siblings and the staff, and are rarely anywhere near, let alone in, their assigned beds.

I was eventually directed to a small child sitting quietly on his mother's knee, facing away from me, observing the activity in the room. His father sat beside him, trying with little success to interest him in a picture book.

As I was introducing myself to the parents, the child turned and looked up at me with a beaming smile. He reached up to me with both arms, indicating he wanted to be held. The tell-tale features of Down syndrome were obvious.

I lifted the child up and held him to my chest as I began the routine of history taking from the parents. The child played happily with the stethoscope hanging down in front of him, dribbled down my shirt and ignored the pleas of his embarrassed parents to return to them.

This was their only child. They were not young, and I thought to myself that they probably would not have further children. As I talked to them, their anxious eyes never strayed from their son. They had never parted with him before and their reluctance to entrust his care to others was obvious. I tried to reassure them that all would go well with the operation and that I would take great care with him, but I failed to allay their concern. I was touched by their shy anxiety and devotion to this child.

None of the parent's anxieties spread to the child, who continued to smile and play with my stethoscope. Later, sitting on his mother's knee to be examined, he showed intense interest in me – this stranger who was looking at his hands and feet. When I lent forward to auscultate his chest, he delicately touched my moustache, before moving on to examine my necktie. Everything appeared new, interesting and pleasing to him.

Despite my years of experience, I have always been anxious about anaesthetising children with Down syndrome. Their chubby limbs make intravenous access difficult and once anaesthetised their relatively large tongues, small airways, abundance of secretions and poor muscle tone make them prone to airway obstruction. In addition, there's always concern about atlantoaxial instability in the cervical spine, making it necessary to take great caution moving any such child under anaesthesia.

Not wishing to increase the parental anxiety, I didn't speak of these concerns. I reiterated that I would take good care of their son and arranged to meet them outside the operating theatre before the procedure. The child happily waved me goodbye, seeming pleased to have made a new friend.

That afternoon the child appeared to recognise me immediately when I walked out of the operating theatre into the crowded holding area. He excitedly pointed at me and once again smilingly reached up to be held. Once again, his parents appeared anxious and embarrassed by this overly familiar behaviour, while reluctantly releasing him from their care.

I held the child close while offering further reassurances to his parents. In response to his mother's coaxing, the child placed a sloppy kiss on the cheek of each parent, followed by a gallant wave to all in the room as I carried him to the anaesthetic room.

I laid the child on the trolley and as the nurse assistant went through her routine of applying monitors and trying to distract him, I searched for a suitable vein for administration of the anaesthetic agents. The child, not interested in toys or games, was intent on watching his new friend and the cannulation procedure.

As I feared, the chubby hands and feet hid the veins I hoped would appear. I tried one hand, and failed; a haematoma formed and I moved to the other hand. Again, I failed. The child remained silent and calm while watching these attempts, but would flinch slightly as the needle entered his skin, and look up at his new friend's face, trying to understand why this hurt was happening.

I moved around the trolley and starting tapping the child's feet, first one, then the other, willing the faint blue lines to appear, again without success. I was now becoming desperate to put an end to this ordeal for both of us.

I had always hated hurting children when placing cannulae but with skill, distraction and speed, the hurt for most children was transient, minimal and quickly forgotten. Sometimes children would cry or need to be restrained and this always distressed me.

With this child it was different – and worse. This child could have no understanding of why this was being done to him, yet still looked at me with trust and affection. I hated myself for hurting him and betraying his trust in me.

The room was hot and stuffy and I could feel the sweat on my forehead as I moved back around the trolley to look at the child's hands again. I tapped and tapped as the child silently watched every move. Finally, a faint blue line appeared. I paused, glancing at the child's face, so full of affection and innocence, before piercing his skin with the cannula.

A quick flush of blood indicated success. I sighed with relief, wiped my sweaty brow with my sleeve and leaning forward, began to tape the cannula in place.

It was then that I felt the wet, slow dribbling soft kiss on my cheek. Looking up, I saw my patient sitting up, giving me a broad forgiving smile and reaching out his with other arm to once again be held in my arms.

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An Outsider Looks In

Jennifer Barry, Project Director, RCH 150

One of the pleasures (and secret powers) of being an 'outsider' to an organisation - and, by extension, the community that surrounds it - is that you can view things for the first time. Fresh eyes let you 'see the wood' among the trees and ask the questions others are either too embarrassed to ask, or have forgotten to raise.

I started at the Royal Children's Hospital in September 2017 as Project Director of the RCH's 150th Anniversary. Recognising that I have a short window of opportunity to 'see the wood' before the forest starts closing in, and in an attempt to gain as much insight as I can into what the RCH means to its diverse stakeholders, I have thrown myself into meeting as many people attached to the hospital as I can. I have asked lots of questions and heard many stories. I've walked the corridors, nooks and crannies of the RCH campus like a flâneur, quietly observing staff, patients and families as they go about their business. It has been a richly satisfying experience and, in the spirit of giving back, I'd like to share some of my early impressions.

Firstly, a workplace filled with children is a delight! This may be obvious to those who have worked in paediatrics for years but, to an outsider, it's a complete revelation. Most workplaces are 'grown-up' places where 'serious' adults go about their 'serious' business, but here the RCH's very reason for being runs around in front of you every day. I love seeing kids, excited by the prospect of a tasty treat from one of the shops on Main Street, in deep negotiations with their parents about what burger or ice-cream they want, (kids will be kids and no strange medical harnessing is going to stymie their satisfaction!). I love seeing them play among the gigantic legs of Creature or jump up to swipe the interactive screen, sending fluorescent geometric shapes on an animated collision course with each other. And I love seeing the look of wonder on their faces when a rainbow coloured poodle from the Lort Smith casually walks by ("Did you see that?"). It seems to me that, having children surrounding us every day is the greatest privilege of working at the RCH and the greatest reminder of what brings us all together.

My second impression is this: no matter what role or connection someone has with the RCH, they wear their love for the organisation on their sleeve. Whether someone is a current or former staff member, a current or former patient or family, a donor or fundraiser, the force propelling them onward is their passion for this public institution. Everyone I've met has been willing to sit down and share their stories and experiences of the RCH with me; and not in a perfunctory way. Some of the stories told go back decades, chronicling medical innovations and personal professional milestones that are clearly carried with pride. Some stories are local, others reach across the world. Others tell stories of celebrity encounters or important occasions with the Queen. Still others share stories of small, private moments with patients or parents that deeply affected them.

Finally, the thing that has impressed me the most since starting here at RCH is the sense of possibility that permeates the place. The hospital doesn't feel like a staid, old institution with its primary interest being maintaining the status quo. It feels like a place that is open to new ideas and new ways of working – not just from a medical perspective but across all aspects of business. It feels like an organisation that, while proud of its (almost) 150 year history, is not burdened by it. From my humble outsider perspective, that's terrific. In fact, this youthful curiosity – this buoyant anticipation – might just be the secret to the RCH's vigour. Perhaps, like the many children it serves, the RCH is an eternal child; always inquisitive, always looking for the next adventure? But this Peter Pan quality is not just charming, it's smart. The writer and philosopher, Aldous Huxley, said: "The secret of genius is to carry the spirit of the child into old age, which means never losing your enthusiasm." As we approach the RCH's 150 year anniversary, this sage advice seems particularly relevant.

Off the back of these initial impressions, it is a great honour to join others in their love for the RCH but, if I'm honest, it also fills me with some apprehension. As an outsider, I worry that I won't be able to do justice to the many people and stories over the past 150 years that have made the RCH what it is today. There are so many people who should be acknowledged; so many stories that could, and should, be told. The good news is that the 150th anniversary is still a few years away and this gives me enough time to listen to many incredible people, ask dumb questions, and really immerse myself in the inspiring history and curious future of the RCH. It also gives me enough time to transition from an outsider to an insider...

Coming from a background in art and public programming, I have no prior experience of working in the health sector of any kind and I must admit I have medical-vocabulary-envy (it would be so cool to actually understand the medical terms I hear every day). Given a medical career this late in the game is unlikely, I'll have to content myself with contributing my own area of expertise to the 150th anniversary celebrations (and I'm looking forward to doing this with every arty skill I have). But I need you all of you – to help me bring it to life.

Share your stories, ideas, and passion for the RCH with me so that, together, we can make the 150th Anniversary of this wonderful institution the best, and most inclusive celebration in the hospital's long and illustrious history.

If you have a story you would like to share or any ideas on what you would like to see included as part of the RCH 150th Anniversary Program, please contact Jennifer Barry, Project Director (RCH 150), on 9345 9484 or by email: jennifer.barry@rch.org.au.

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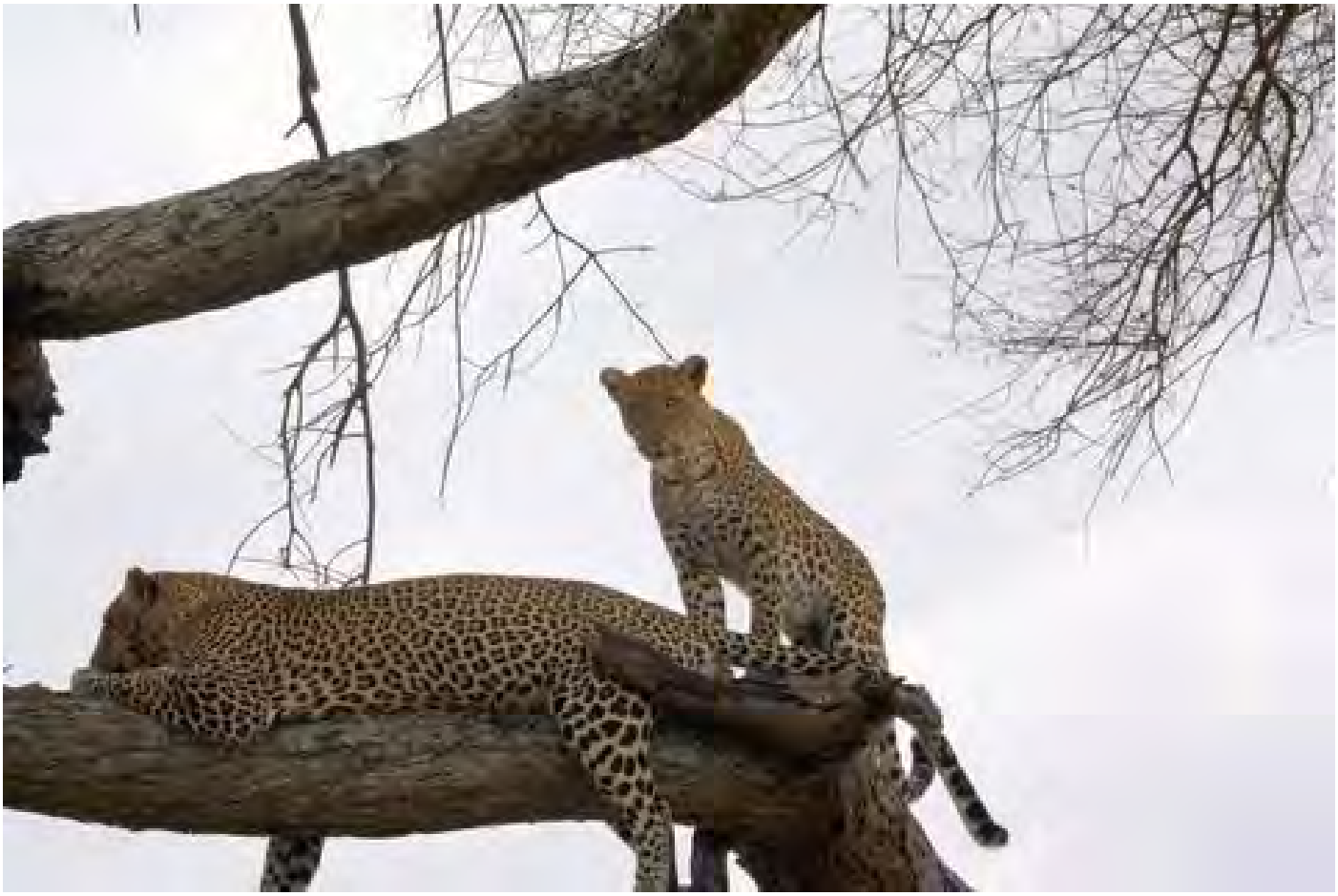
Leopards

photos by Hugo Gold



Cheetah in Kruger National Park

photo by Jim Wilkinson Return to Main Menu