Report on the 9th Continental Meeting of the International Society of Paediatric Oncology (SIOP) Africa held in Accra, Ghana, March 2010

Theme “Childhood Cancer in Africa: Improving Access to Care”

Prepared for the Cancer Association of South Africa in acknowledgement of a travel grant. A letter of thanks is attached, as are the abstracts of my presentations. A full summary of activity follows.

This was the 9th international meeting of the paediatric oncology meeting was held in Accra. There were parallel sessions for doctors, nurses and parents.

Wednesday March 10

The local organiser, Lorna Renner, and the president of SIOP Africa, Janet Poole, welcomed delegates.

SESSION ONE

Mariana Kruger started the proceedings with an ethics presentation dealing with the rights of hospitalised children and adolescents, suggesting that there may be room for a set of African guidelines. Peter Hesseling is widely known for his pioneering work in developing low intensity protocols for Burkitt Lymphoma. He delivered the Walbeck Lecture in which he detailed the development of these treatments and compared the results to groups like FAPOG and INCTR. His work is nicely summarized in a recent paper in the Journal of African Cancer 2009; 1: 72-79.

SESSION TWO

Janet Poole continued the morning with a talk on HIV related Lymphoma. While there is some controversy over the degree to which rates of NHL have risen in the time of HIV, there is unanimity on the fact that with HAART, standard chemotherapy regimen can be used without excessive toxicity. Cristina Stefan discussed Kaposi Sarcoma whose incidence has risen dramatically with the HIV epidemic. It is both preventable and treatable with HAART with or without specific chemotherapy. There were talks on Burkitt Lymphoma from Morocco (on behalf of the French Group FAPOG) and the Cameroon, and there was an input on the usefulness of culturally meaningful disease explanations by a Norwegian anthropologist. I presented the data on malignancy in HIV-positive South African children and discussed the Red Cross Children’s Hospital experience with AIDS-related lymphoma. David Stones from Bloemfontein provided an encouraging view of the improvement in outcomes being achieved for malignancy in HIV-positive children since the HAART rollout.

SESSION THREE

Kate Mathay spoke about the approach to abdominal masses – this was aimed at trainees and shared-care paediatricians in the audience. Trijn Israels discussed the management of Wilms tumours in LICs where the survival gap (between these countries and the developed world) is the result of late presentation and abandonment. This was followed by a mixed bag of solid tumour presentations. Good results are being achieved for nephroblastoma in Morocco and Ghana which is encouraging. Treatment of Stage IV NB over the age of 1 year in Morocco had (unsurprisingly) dismal outcomes – 8/99 (8%) in CCR. Epidemiological data from Ghana and Nigeria showed the most common tumours to be
Lymphomas (mainly Burkitt), Retinoblastoma and Wilms Tumour. AML was more common than ALL in Nigeria (we have observed a similar trend in black South Africans) but not in Ghana.

At the end of the day’s proceedings the delegates proceeded to the Kwame Nkrumah Memorial Park for a brief but moving opening ceremony.

**Thursday March 11**

**SESSION ONE**
Past president of SIOP, Tim Eden now heads up World Child Cancer. Established in 2007, WCC is dedicated to redressing global inequalities in access to treatment by funding twinning projects. Projects are open in Malawi, Colombia, Mexico and the Philippines and in the planning stages in Mozambique, Ghana, Namibia and Nepal – it is envisaged that four new projects will be launched each year. Tim showed his insights into the potential of twinning projects to transfer knowledge, experience and technology. The talk was entitled “Childhood Cancer in Africa: Improving Access to Care” and served as a keynote address for the whole meeting. Dr Ama Edwin from Accra discussed stress management among childhood cancer health workers.

This was followed by a number of talks on Acute Leukaemia. Scott Mc Farlane leads the New Zealand Paediatric Oncology Steering Group Pacific Island Project. They have designed a series of targeted interventions using low intensity protocols appropriate for this disparate group of resource poor islands. Different approaches are in use based on local capacity and referral patterns. Where the leukaemia is deemed untreatable, comprehensive palliative care protocols are available.

I missed a discussion of a twinning project between Madrid and Asuncion focused on childhood ALL because I attended the parent and family session briefly. I went to listen to the brother of a Ghanian patient of ours talk about his experience as a sibling of a cancer patient. It was as moving as it was revealing.

Leukaemia outcomes remain limited: the Ghana group reported remission induction for ALL of 70% but only 24% remains in CR (not all have completed therapy). No children with AML are in CCR off treatment. Burkitt Leukaemia treated in Morocco with LMB-89 achieved only a 44% overall survival, and the survival for AML favourable, intermediate and unfavourable risk groups (by cytogenetics) was 41%, 25% and 10% respectively. Interestingly most patients in the favourable risk group had t8;21 (31) compared to very few with inv16 (2) or t15;17 (1).

**SESSION TWO**
I chaired this session along with Max Copper (the treasurer of SIOP). Ravi Ravindranath discussed the challenges in multimodal treatment of retinoblastoma, a highly curable tumour when diagnosed early. The latest COG protocol is comparing VC to VEC as standard therapy. Despite the emergence of new local treatment strategies aimed at preserving sight, low income centres need to concentrate on early detection to decrease the proportion of disease that is incurable at presentation. To this effect Kahaki Kimani, an ophthalmologist from Kenya, described the Kenyan National Retinoblastoma Strategy. The programme aims to increase awareness of and mobilise resources for RB through four working groups (awareness, medical care, family support, resource mobilisation). Adobea Esseman debated the parlous state of affairs in Ghana where patients present with advanced disease, and there is widespread refusal of care or abandonment. A report from Casablanca was somewhat more encouraging but still 18 of 69 patients (26%) were lost to follow up.
during or just after treatment.

Gabriele Calaminus gave an update on paediatric brain tumours. Referring to all the major tumour types she discussed the diagnosis and management making reference to SIOP protocols (This talk was switched with Hans Peter Wagner (Friday Session 2) but I discussed it here to put the oral papers in context). In broad terms she discussed the pre-operative workup, post-operative imaging (preferably in the form of an MRI within 48 hours) and staging (MRI spine and lumbar CSF cytology at day 14), as well as further management (chemotherapy and/or radiotherapy) with a focus on multidisciplinary care. Hesham Hussein from Cairo presented a series of medulloblastoma (20/23 non-metastatic) treated with 2 cycles of chemotherapy pre-XRT. Three-year overall survival was 50%. Dr Bendani from Morocco presented a series of patients (mostly medulloblastomas and ependymomas with a few astrocytomas).

Marc Hendricks presented the Red Cross Children's Hospital experience with extracranial germ cell tumours. Excellent results have been achieved using a combination of surgery and JEB chemotherapy (overall survival of 92.8%). A significant saving can be made in terms of GFR and Audiogram testing and myelosuppression was not excessive.

The session was brought to a close by Leila Hessissen of Morocco who discussed the My Child Matters Initiative – the Moroccan project is a national campaign to increase the early diagnosis of childhood cancer. They have fashioned a dynamic campaign which has raised the profile of childhood cancer considerably.

SESSION THREE
The session started with lectures by Kate Mathay (Oncological Emergencies) and P. Kerkure (Supportive and Palliative Care). I chose to attend the nurses’ session at this stage because our professional nurse, Barbara Olsen, presented her talk on “Facing the challenges of caring for paediatric oncology patients with central venous access devices.” It was a state of the art exposition of central line care which was very well received.

I returned to the main programme as the poster session commenced. It proved to be quite lively. Barbara Olsen presented our nursing poster which dealt with increasing awareness of chemotherapy related extravasation. There were a number of very engaging presentations including one from Leila Hessissen of Morocco which looked at how many patients were using complementary and alternative therapies (68%), what they used and how many of them informed the treating physician (20%). This may be an interesting area for research in Cape Town. We do know that many of our patients use complementary therapies, but it would be useful to document just how many and, in cases where we are not informed, to examine the reasons for not doing so. David Stones from Bloemfontein presented data showing a relatively constant disease profile over time with more cases of low stage disease and improving overall survival rates. This is very encouraging. There were posters on Burkitt lymphoma in the Cameroon, Cote d’Ivoire, Morocco and Nigeria, and posters on almost every from of childhood cancer including bone tumours.

Friday March 12

SESSION ONE
The session started with a state of the art lecture on Allogeneic Bone Marrow Transplantation by Maarten Egeler – the current SIOP President. He made particular mention of new developments in the form of haploidentical transplants, mesenchymal stem cell infusions and natural killer cell manipulation.
Greg Reaman, who leads the COG clinical trials group, gave a very inspiring talk on the impact of clinical research collaboration on improving outcomes for children with cancer. He identified some major lessons:

1. physical/psychosocial cost of cure
2. risk benefit ratio of therapy intensification
3. transplant is not the sole solution for refractory or relapsed disease
4. competition, while intellectually stimulating, does NOT always lead to success.

In terms of the potential impact of global collaboration he stated the following:

1. Information exchange and technology transfer
2. Protocol development
3. Education and training
4. Research in survivorship.

Three short lectures followed. [1] Marcello Scopinaro reflected the evolution of management, and discussed current treatment guidelines, particularly without radiotherapy. [2] A pathologist from Ghana, Dr Wiredu spoke about Optimising diagnostic capacity, and laid out the problems and challenges, quoting George Bernard Shaw … “Submission of specimens with no clinical information is a subtle tribute to the omniscience of the pathologist but is diagnostically useless.” [3] Verna Vanderpuije discussed radiotherapy in Africa. It is accessible to only 20% of the population in only 25/53 countries (assuming all the machines are working). There are 0.2 machines/million compared to 5 machines/million in Europe. What the radiotherapist needs in order to deliver a good service is accurate information about the clinical presentation, details of the surgery and comprehensive pathology. What the continent needs is more machines and regular maintenance.

SESSION TWO
Hans Peter Wagner (speaking on Thursday Session 2) gave a talk entitled “What has been learnt from the PODC?” He discussed the following lessons:

[1] He emphasized the importance of twinning.
[2] He spoke about the need for effective treatments – they should have an efficacy of 50% and toxic deaths < 5%; they should be affordable and require only short periods in hospital.
[3] Drug policies are important ... essential drugs should be identified and accessed at the lowest possible cost.
[4] He praised the power of the internet ... e.g. Cure4Kids; the POND database.
[5] He spoke about the need for accurate outcome measures. When reporting outcomes we need to consider [a] % Having Access to Care [b] % Diagnosed [c] % Treated [d] % Cured. If one only considers how many of those actually treated are cured then one arrives at falsely inflated survival figures.

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<th>Level</th>
<th>% Having Access to Care</th>
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<th>Overall Survival</th>
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<td>1</td>
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He concluded by reminding us that it’s vital to quote survival as a measure of all children diagnosed and NOT only those whom are treated.

Bharat Agarwal – SIOP secretary general - discussed “Improving Access to Care: One Step at a time ... What’s learnt from the Indian experience?” He delineated the following steps:
A series of oral presentations followed. Leila Hessissen spoke about the approach to palliative chemotherapy in Morocco which precipitated lively debate. Linda Wainwright presented the experience of Chris Hani Baragwanath with malignancy in adolescents. She ascribed the overall poor outcomes to generally poor awareness and delay in diagnosis. She suggested a set of Warning Signs for Adolescents. Emma Johnson spoke about the management of low risk febrile neutropaenia in Edinburgh. All patients are admitted on IV antibiotics but then discharged on oral co-amoxiclavulanic acid if they are well [CCLG Framework Document – a framework to be incorporated into local guidelines]. I presented a study of the usefulness of tumour markers in the detection of solid tumour recurrence. Mariana Kruger finished the session with a paper dealing with the ethics of managing rare diseases.

**SESSION THREE**

Rada Ladenstein spoke about the central role of parents in multidisciplinary management. Leila Hessissen showed a video and gave a presentation about the role of parents associations in supporting paediatric oncology units in Morocco. Assistance includes material support for cancer treatment, transport, housing and schooling, as well as the provision of a psychologist and a social worker.

The meeting closed at 15h00.

In summary this was a very useful meeting. There were doctors, nurses and parents from all over the continent and it was the perfect opportunity to establish and maintain relationships.

Cape Town will host the next SIOP Africa Meeting in March/April 2012 and we hope we can count on CANSA for support.

Thank you again for your generous donation.

Alan Davidson
April 2010