DRASH FELLOWSHIP REPORT: DR. THEREZ PILOYA, September 8, 2014

INTRODUCTION

I am a paediatric endocrinologist who graduated from the ISPAD/ESPE fellowship at the Pediatric Endocrinology Training Centre for Africa (PETCA) in Nairobi in 2012. I and Dr. Beatrice Odongakara were the first paediatric endocrinologists in Uganda. I am the paediatric endocrinologist at the Mulago National Referral Hospital and Teaching hospital for the biggest and oldest University, Makerere University in Kampala, Uganda. Beatrice is the paediatric endocrinologist at the Gulu Referral Hospital and Teaching Hospital for Gulu University which is found in the northern part of Uganda. To date, we have 3 paediatric endocrinologists in Uganda. This number of specialists is a drop in the ocean for a country whose population is ~34 million with about 50% of the population being less than 15 years old.

Mulago Hospital runs the biggest paediatric diabetes clinic in the country with about 150 children and adolescents registered in the clinic. As our endocrinology program in Uganda is still in its infancy stage, a lot of mentoring and support is needed for us to take it to the next level. Therefore, in the quest to improve the quality of paediatric diabetic services in the hospital and subsequently in Uganda, I applied for and received the ISPAD Allan Drash fellowship. My specific aims for this clinical fellowship were:

1. To gain experience in running a paediatric diabetes programme with a multidisciplinary care team approach including nurse educators, psychologists and dietitians.
2. To gain experience in patient- centered care including developing a patient/family education curriculum that encourages self-management skills.
3. To spend time at the diabetes camp with the goal of starting/improving diabetes camps for children in Uganda.

ELECTIVE SITE

I was awarded this fellowship in 2013 to spend time with Antoinette Moran as a mentor at the University of Minnesota, USA. University of Minnesota Children's Hospital is located on the Mississippi River in Minneapolis and is affiliated with the University of Minnesota Medical School. The hospital provides a broad range of paediatric programs including the Division of Endocrinology and Diabetes, which is headed by Dr. Moran and consists of 7 endocrinologists, 3 fellows at different levels of training, 2 diabetes nurse educators, 1 diabetes nurse practitioner, a dietitian and psychologist. The diabetes clinic runs Thursdays at the main hospital, with other diabetes clinics in satellite hospitals on different days.

FELLOWSHIP EXPERIENCE

I arrived in Minnesota on 21st July 2014 together with Dr. Beatrice Odongakara, who Dr. Moran was also sponsoring. We stayed in a University apartment near campus and near the bus route. Our rotation lasted 6 weeks in Minnesota getting experience in both endocrinology and diabetes but focusing on diabetes. On the first day of our visit, we had an orientation, introduction to the team and setting up the schedules for the rotations and we reviewed the objectives of the fellowship. Following the 6 week rotation, we travelled with Dr. Moran to the ISPAD meeting in Toronto, from which we left for home.

Diabetes Clinic

The diabetes clinic at the Minnesota Hospital is a full day clinic (7:30 am to 5:00 pm) with approximately 20 patients seen each day. Each week the clinic is run by a least 2 paediatric endocrinologists, assisted by a fellow, dietitian, 2 diabetes educators and a psychologist. Blood glucose recordings are downloaded and HbA1c measured and reviewed before the patient sees the physician and this was intriguing, as compared to our setting where the patient's HbA1c may not be available to discuss with the patient during the visit.

At the clinic, we worked together with the paediatric endocrinologists during the consultations and this was a great opportunity to observe the interaction between patients, their parents and the physicians with dealing with their diabetes. The clinic has a varied population in terms of socio-demographics (age and sex), socio-economic status, glycemic control and cultural variations thus each patient's diabetes management was unique and this was a rich clinical experience because of the applicability in our setting.

We also learnt enormously from the other team members, especially the nurse educators and dietitian. We attended the sessions of the latter during the clinics and this empowered me with better skills in management of diet in diabetes. I got to appreciate practical diabetes self-management through diabetes education. In comparison to Uganda, where the diabetes team model is incomplete with many of our centers lacking dietitians and educators, the efficiency and the importance of their roles needs to be emphasized.

There were research projects running at the clinic during our clinical fellowship. We closely followed the process of obtaining consent and recruitment of the participants at the clinic. This was a great opportunity for me to reflect on the use of operational research in our settings to improve our clinical care. We also attended one of the satellite diabetes clinics in Minneapolis as well as a satellite clinic in another city, Duluth. The structure of the clinics is exactly the same as the one at the main University Hospital in regards to the human resource and system management.

The endocrinology division had weekly meetings every Wednesday to discuss challenging patients. This was a great opportunity for me to learn from other team members, clarify any ambiguity and get to discuss up-to-date diabetes and endocrinology management. These meetings were very helpful in understanding the reasons why different things were done in usual practice.

The Diabetes Camp

The diabetes camp was held at YMCA camp St. Croix in Hudson, Wisconsin, 10th August to 16th August 2014. Over 400 children and adolescents with diabetes attended the camp, including the day pointers (children aged less than 8 years who only attended during the day), and those aged $\geq$ 8 years who stayed in the camp for the whole week. The children were grouped into cabins depending on the age and sex. Each cabin had a maximum of 8 children with 2 counselors and a medical staff member allocated to them. The counselors consisted of former paediatric diabetic campers and non-diabetic youth trained on how to manage diabetes. Their role was to oversee the children's activities, general social care, and supporting them with blood glucose testing, insulin management and identification of any acute complications. The children and the camp

teams were involved in various activities which included hiking, canoeing, and various games in and out of camp.

The medical staff role was to provide medical support to the children and counselors. We worked closely with a paediatric endocrinologist and were allocated 2 cabins; a total of 16 children to take care of during their stay. We were to guide them with their insulin adjustments, using decision making in regards to the activity and food at the camp. We would treat the children with any acute illness. It was a great experience to learn from the children, counselors and medical staff but I also put to practice the knowledge that I had acquired in the first 3 weeks of the clinical fellowship.

Lessons Learned at the Camp

- A big proportion of the children have a basic knowledge in self-management of their diabetes which further stressed to us the necessity of good diabetes education.
- The role of peer education and peer support was very alive at the camp and very inspiring. Peer education is very important in our setting with limited trained health workers in diabetes. These peers maybe used as educators to back up the diabetes teams at our clinics.
- Role modeling as a key tool in assisting the young diabetes patients cope with diabetes. At the camp a former American football star of Minnesota with diabetes was brought to talk to the children, and the children were really inspired by him. One child said "*I did not think we could do such difficult things but he says it's possible with good care, wow*."
- The camp teaches the children some degree of independence from their parents in diabetes care.
- The camp empowers the children, especially the counselors, with leadership skills.
- Children at the camp learn practical management of their diabetes without having to sit in a didactic lecture.
- I got practical exposure to management of diabetes with insulin pumps.
- Camps are also team building activities; social gathering where you get to socialize with people from the different cadres of care including patients and counselors, share challenges and successes of diabetes care at each level, discuss different cultural aspects of life including health care, learn new games, and have fun.

Other Experiences

In addition to diabetes clinics and diabetes camp, we participated in the in-patient attending rounds for endocrinology and diabetes, attended endocrinology clinics (general endocrinology, bone health, disorders of sexual differentiation, obesity, and brain tumor clinics) , and attended general pediatrics in-patient rounds.

CHALLENGES

- Some of the exposure to and knowledge of technology we got like the pumps and continuous glucose monitoring may not easily be utilized in our setting because of unavailability.
- We did not get a chance to manage any child with diabetes with acute inpatient complications like diabetic ketoacidosis and severe hypoglycaemia which are commonly seen in our setting, because these did not occur at the University during our stay.

- Being that we are not registered as medical personnel by the United States, our engagement with the patients was only limited to observership and thus it was very restrictive.

SUGGESTIONS

- This fellowship is very useful for the endocrinologists who trained in a resource limited setting to get to learn the ideal management of children with diabetes.
- The 6 week rotation is adequate for an observership, however, for practical hands on clinical attachment for skills this time would be insufficient.

DR. MORAN'S REPORT

Drs. Piloya and Odongkara spent 6 weeks in Minneapolis as outlined above. I obtained philanthropic funding to cover Dr. Odongkara's visit as well as costs above $5000 for Dr. Piloya. We attempted to give them an in-depth diabetes outpatient experience (mostly at the University but also at outreach clinics) as well as attending diabetes camp. In addition, they attended diabetes and endocrine in-patient rounds, a few general pediatrics in-patient rounds, and a smattering of endocrinology clinics. They worked with one of my colleagues and an endocrinology fellow to develop an African arm of a pediatric bone research project (researching vitamin D metabolism in Minneapolis Somali immigrants; they will join as coinvestigators with Ugandan patients at Mulago and Gulu). In addition, we gave them some Minnesota cultural experiences (hiking in the north woods, a small town polka festival, fishing on a lake in rural Minnesota, the Mall of America, fireworks over the Mississippi River, the Minnesota State Fair). It was a pleasure having them here, and everyone on my team enjoyed working with them. The diabetes dietitian and I will visit them in Uganda in November and we are discussing ways to move forward with diabetes research and clinical projects (including diabetes camp). It was useful having the two of them here together, both because they will be working together on projects when they return home, and because while they were in Minneapolis I believe it allowed them to feel more comfortable getting around on their own. My only suggestion for future Drash fellowship sponsors is to recognize that the visa process takes much longer and was more expensive than we anticipated (because they were here for more than 4 weeks we had to do the more involved student visa rather than a visitor visa).

COSTS FOR DR. PILOYA (the costs for Dr. Odongakara were equal, these are the costs for just one person).

Airfare*	2500.79
US visa (cost for Terry in Uganda)	160.00
US visa (cost for UM SEVIS)	475.00
Rent	1462.00
Bus/light rail pass	124.00
University health insurance	207.00
Food and incidentals	830.00
Canadian visa	90.00
TOTAL	**5848.79**

*Note: airfare would have been less expensive if I had not routed them through Toronto for the ISPAD meeting. They roomed with me in Toronto and I covered all their costs at that meeting, which are not included in the above assessment.