

Tutors:

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Tutor Report January 2009

Third month for the 2nd group of fellows, who came back after Christmas/New Year holiday after up to 1 week delay due to problem with VISA. This was expected, since they not had obtained "pupil pass". Now work is ongoing to solve this (Responsible: Rispa, project assistant). To follow up.

Weekly schedule:

Monday: endocrine-oncology clinic, Kenyatta (every 2nd week)
Tuesday: endocrine-diabetes clinic, Kenyatta
Wednesday: endocrine-diabetes clinic, Aga Khan
Thursday: endocrine-diabetes clinic, Gertrud's
Friday, every 2nd Monday seminar presentations, the rest of the time own work and presentations of patients, Journal Club and different growth publications.

Topic of the month: Growth

This month was devoted to growth. In parallel to CDC percentile curves also the Swedish SD-score curves was introduced: 24GV-20 yr for Length/Height, Weight, Head, BMI, and with target height. Seminars were given by the fellows on all growth periods: foetal, infancy, childhood, juvenility and puberty; as well as 2 theses devoted to normal growth, one from UK Gary Barker and one from Sweden, Lars Gelander. The reference articles for the WHO growth charts 0-5 yr new and old up to 18 yr as well as for the Swedish were read and discussed and growth measuring technique was implemented in practice. Three thesis were discussed:

Berit Kriström: GH treatment

Chatarina Löfqvist: GH and IGF methods

Birgitta Lannering: Brain tumors in children including endocrine sequelae as growth and GH treatment.

Administration of the program

Most of KAW work this month was focused on different parts of administration of the program, whereas BK took care for the clinics the last two weeks.

Clinical setting

GOAL: In all three hospitals to have a clinical team working with the program patients. All three hospitals approved to allocate a *pediatric nurse* to be devoted to the program: to take care of organization, and to be educated in parallel to the fellows in order to be able to take care for patient and family information both in diabetes patients and in endocrine patients. To have *nutritionists* involved; at every Tuesday of Kenyatta, and every 2nd week at Gertrud's. The nutritionist will be educated in diabetes in children and in different endocrine diseases by working jointly with the fellows and the tutor of the program.

At the end of the month the following was reached:

Kenyatta: Nurse, educator and nutritionist from the adult diabetes unit came (thanks to Atieno) and will continue to come to the paediatric unit on Tuesdays to work under leadership of Lucy Nyakio.

AgaKhan: Prof W M

will talk with the head of the nurses (who was away in January), for selecting a nurse to work with the program under the leadership of Mary Limbe.

Gertrud's: Announcement was out for a position as a program nurse. To be interviewed by Dr Paul Lagong and Dr Sidney Nesbitt, and work with the program under the leadership of Paul Lagong.

Patient Records

See previous reports from Nov 2008: Martin Ritzén, and Dec 2008: Stefan Aronson.

It was not possible (due to legal issues) to turn to one computerized patient record form only, as suggested by Martin Ritzén. However, approval was obtained from the hospitals to start with *structured paper versions*; one for new patients, one for return endocrine patients, and one for return diabetes patients. Both shortterm and longterm plans are to be written down, in order to facilitate the takeover of both fellows and tutors within this program.

The original is kept in the clinic file, and a *copy at the office* of the program at Gertrud's.

Next step will be to put this information into the computer. Nordinet 3.0 version from Novo Nordisk. This software will be possible to use for all patients belonging to the program in the 3 clinics, and will not interfere with the archives of the patient records of the three hospitals. The database will make it easy to keep track on number of patients per diagnose, the need for different laboratory analyzes as well as for need of hormones and drugs.

KAW to follow up with Mariann Skafte Florin, responsible for Nordinet worldwide. Which are the legal requirements?

Patients registry

As a first step, all patients enrolled to the program got a *Green Registry Card*, with info of identification: name, sex, birth date, address; diagnose, visit dates and drugs, "economy"; i.e. 1) pay privately, 2) pay by insurance, 3) can not pay; in order to keep record on the proportions between these groups, and the need for a trust fund to be developed.

Pharmacy contact

Several meetings with chief pharmacist Robert Nyarango at Gertrud's together with dr Paul Lagong. Finally, there now is a computerized drug list, both at the program and at the pharmacy at Gertrud's, who will keep order for the 3 hospitals. By keeping track on the Green Registry Cards with information of number of patients on a specific diagnose as well as amount of drug, it will be possible to estimate need of drugs for the coming 3 and 12 months, respectively, in order to avoid lack of any drugs. (For instance, during January, Kenya was out of Hydrocortone, and some at patients got it from Kerstin and Berit, whereas others had to shift to Prednisolone.)

From now on: *A monthly meeting, Friday 2nd week, with the chief pharmacist Robert Nyarango at Gertrud's has been scheduled with the fellows, tutor and dr Paul Lagong (Lucy and Mary welcome).*

Laboratory

Contact was taken with the chief of the laboratory/pathology unit at Gertrud's, Dr Angela Mayo 0733-617678 together with Peninah Chege 0722-790250, from the lab. All methods used was listed, in order to evaluate the relevance of the methods for pediatric ages, the availability and the price. At Gertrud's there is a BioMerieux equipment that today measure TSH, T4 and T3 as well as LH and FSH.

From now on: *A monthly meeting Friday 2nd week with Dr Angela Mayo and Peninah Chege with fellows, tutor and dr Paul Lagong (Lucy and Mary welcome).*

New: From January, 17-OH-PROGESTERONE analyses in CAH patients can for the program patients be sent to Huddinge laboratory (KS) free of charge on filter paper. Initiated by Martin Ritzén

New: IGF-1 and IGFBP-for serum on filter paper, will be possible to send to the laboratory at Växthuset in Göteborg, also free of charge initiated by Kerstin AW, who also will check and come back for information regarding GH, testosterone, oestradiol, SHBG.

Hopefully, these two examples will be followed by other analyses of laboratories of the tutors in the program. By that, we can assure that the methods used are appropriate for children.

Moreover, the costs for analyzes will be reduced.

To follow up: still not received all information of the methods used at the two private laboratories to which the Gerturd's lab sends the sample for analyses or to be shipped abroad.

Patients

During this month we focused on education and involvement in the treatment, of both patients and their parents.

New patient categories with management plans was intitiated:

JOINT ENDO-ONCOLOGY CLINICS

Goal: to evaluate and treat endocrine sequele, to develop management plans.

During January, a new clinic for the program was initiated on Mondays at Kenyatta: joint endocrine-oncology clinics. For the 1st time the paediatricians was able to follow up endocrine sequele in the oncology patients treated by prof Mwanda at Kenyatta. A dream of Lucy came true! Thus, we first started with questionnaires for endocrine sequele and careful height/weight and parents height measurements. A first draft of a structured patient record form was used as a base for further improvement. First clinic had 12 children with oncology diagnoses. Responsible Lucy Nyakio.

GH TREATMENT IN CHILDREN WITH GHD

Goal: substitution therapy.

A program for investigation of GHD was introduced.

Four patients are now on GH therapy within the program, with Genotropin available for 2009 only: One 17 yr girl with panhypopit, one 11 yr girl with post-craniopharyngeoma, two 4 yr boys with TSH and GH deficiency. Management plans for these four patients includes monthly visits to the program in order to optimize for the fellows to learn from the clinic of the patients. For education purpose, ideally, there should have been a few more GH treated patients, but first we have to make GH available longterm for the present four patients. (Blood samples before and during treatment was and will be taken to the GP-GRC Laboratory in Göteborg, Sweden).

Remains: Obtain GH longterm for these GHD patients in the program. Injection devices for safety and conveniency. Educational support.

CAH

Goal: substitution therapy.

A management program was developed with repeated measurements of 17-OH-Progesterone (4 samples/24 hour) on filter paper, to be sent to Huddinge laboratory, Sweden. The first 2 siblings started monitoring during January this way outside the hospital setting. However, education and training of the fellows within the programme on the interpretation of the analysis together with growth velocity results is required. Written information to parents was made.

CORTISOL REPLACEMENT

Goal: substitution therapy and to mimic physiology.

In the patients on substitution doses of cortisol, the treatment was changed to obtain a more normal rhythm; with the highest dose as early as possible in the morning, the second at early lunch time, and the third in early afternoon.

DIABETES type 1

Goal: to involve and educate nurses, nutritionist in the management of pediatric diabetes.

During January, the previous structure of treatment (see report by Stefan Aronson) was continued. Efforts were put into the problem how to get information about given insulin therapy in relation to food and activity. Urine checking was reintroduced, growth (height and weight) and puberty staging always monitored and plotted in charts and interpreted together with heights of the parents. Only Mixtard Insulin was available and used, most common in 2-3 doses/day.

DIABETES type 2/Obesity

Goal: to involve nutritionists, for later intervention program.

Several obese patients came during January, and we manage to have the nutritionist involved. Follow up of these patients will be to the same fellow, i.e. the fellow in charge, also after one year.

SMILE CLINIC

Goal: to detect children with septo-optic dysplasia (SOD) and midline defects with endocrine disturbances, for referral to the program.

Meeting with the program organizer dentist Sylvia Noha of the Kenya Smile Clinic at Gertrud's. She will together with her nurses go through all patient records in order to take out the children with known growth/endocrine problems, to start with. The nurses in the Smile Program will start with length/height and weight measurements and also with plotting these in growth charts.

To follow up: Meeting with Paul Laigong and the coming Tutor in Feb/March, in order to go through the Patient Record Forms/and plotted growth carts. To further develop the referral criteria from Smile to Endocrine program.

Improve referral to the program by introducing growth measuring

For educational purposes, there still are too few patients in the program. Therefore, KAW went to the Wellbaby Clinic at AgaKhan, Dr N Ojwang and Dr Rosaline Ochieng, and at Gertrud's, Dr Judy Maye, and to the Satellite Clinics for outpatients of Gertrud's; and to private paediatric clinics. At all places, the weight of the infants were obtained and plotted in a weight chart, mainly the old WHO chart, in which the mean of boys and girls are given together with 3rd centile. Only at one private paediatric clinics, the height was possible to measure and to plot in growth charts.

Since it is disturbed growth; height, weight and their relationship, that mainly is the first marker of chronic diseases in children, not least endocrine, there will be a change in the referral rate to the program, first when length/height will be measured and plotted. This was discussed at all levels of the administration of program in the hospitals. KAW also devoted her lectures at the three hospitals to the usefulness in the clinic of height measurements (and the hormonal reasons behind), in addition to weight.

Decisions that was taken:

1. *develop education modules* for 1 hour, ½ day, 3 days education (growth in practise, GIP) of different professionals (technical steering meeting, steering meeting).
2. *available length/height measuring equipment* - 5 weight scales was given by Berit & Kerstin to the program; 1 movable WHO stadiometer was given, 1st to be used in the project by Mary Limbe, thereafter within the program at AgaKhan for education purposes.
CEO at Gertrud's, promised to buy measuring equipment to all parts of Gertrud's.
3. *Growth charts* available for plotting also length/height and BMI
CEO at Gertrud's decided that Gertrud's will go for the Swedish charts in English (will be given free of charge from the Swedish company for Gertrud's and the program)
A meeting with the paediatrician at the Ministry of Health: Prof Dorothy Ngacha, Dr Renson Mukhwana and Kerstin Albertsson Wikland, in order to understand the plans for the WHO 0-5 yr charts in Kenya, and why it is delayed. How our program can be beneficial for education and awareness
4. KAW was invited back in April for a Growth Workshop at the Kenyan Paediatric Meeting in Mombasa. Also then to follow up 1-3.

Office structure at Gertrud's

In order to make the program more cost effective

1. Network of all the computers of the program assistant, the fellows and the tutor to a server and a printer/scanner.
Status: IT personnel of Gertrud's and Catrin/Rispa received the plan. To follow up.
Two white boards for practical use was bought and put up.
2. The program assistant to receive all documents of the program on the server; now in many different "hands and computers".
3. Status: After a meeting with Angela, Catrin, Dr Renson Mugwhana's assistant, received introduction and instructions and got allocated time to help Rispa with this. Not finalized end of January. To be followed up.
4. There is a need for a skilled program manager.
Status: After highlighting the duties and requirement of this person at 2 meetings with the CEO at Gertrud's, the CEO decided to make a new announcement for a skilled program manager (of Angela's calibre). To be followed up.

Meetings

1. 23 March: Nairobi Paediatric Meeting, Nairobi

Program responsible: Paul Mungai

Program: ½ day endocrinology: Mary Limbe, DM type 2 in children;

the March Tutor, to be decided. Fellows, to be decided; ½ day gastroenterology: Mary Limbe will discuss endocrinology in gastroenterology diseases.

2. 22 April: KENYA Paediatric Meeting, Mombasa

Program responsible: Lucy Mungai

2x2½ hour workshop the day before the meeting.

Morning: Growth Workshop, with KAW as responsible. KAW lecture, fellows, to present cases that was decided in January. Practical measuring technique and plotting in charts.

Afternoon: DM Type 1, with Lucy Mungai as responsible, and giving a lecture. The fellows to present cases.

Grant applications

- WDF received a report of 2008 progress of the program.
- Kenya Awareness of Diabetes. An application to be sent to WDF mid March
Responsible: Atieno Jalango
During January there were a Technical program meeting with Atieno Jalango around this application. Thereafter Atieno Jalango and KAW worked with the application in order to add the perspective both of children and of Diabetes type 1. The Pan African Endo/Diab program is to be a major co-worker, for developing the educational modules and management plans of diabetes in children.
Status: the application went to the economists to add budget. A strategic plan meeting is decided before DL of the application, for which Atieno Jalango got a grant.
- to search for all available sources of funding of the program

Companies for collaboration

Novo Nordisk: During January there were two meetings with the representative of East Africa: Francis Njau (0722-788218) and Walter Matunda (0722-286071) of Novo Nordisk and the tutors and fellows:

Decision was made

- to meet once a month
- NN to give a grant to the next announcement of the program application the 4th in the East Africa Journal
- to introduce Nordinet (KAW will again contact Marianne Skafte Florin, Novo Nordisk, Copenhagen, responsible for Nordinet worldwide)
- NN to deliver to the program: English patient and parent instructions for insulin treatment of diabetes type 1 and for GH treatment
- to develop symptom charts for DM type 1 in children, Swedish. Charts made by Novo Nordisk was given as examples: the fellows will change the text and give advise on different figures (not only white children, for instance), and give back to Novo Nordisk representatives at the February Meeting with Novo Nordisk, in order for Novo Nordisk to have them ready at the Mombasa meeting for the workshop on DM Type 1 in children.

Pfizer: Not possible to reach

Goal: to obtain Endo KIGS for the GH treated children within the program. KAW will contact KIGS, Sweden, Ferah Aidyn responsible world-wide of KIGS.

Smith Kline Glaxo, Linda 0721-916616

Tried to come in contact with them since Judy Maye had a meeting with them, where SKG promised to print the WHO 0-5 yr growth charts for wellbaby clinics.

To be followed up.

Grown Health Care, Crown@crownkenya.com. 00254-2-037-500 00

WHO measures for height and lengths. Tried to arrange a meeting for information about equipment and costs with the fellows.

To be followed up.

Committee meetings in January

During January there were two Technical Committee Meeting and one Steering Committee Meeting and one meeting with the Trustees of Gertrud's.

Technical Committee Meeting: See protocols attached. Decided to preferably be held twice per month also with Paul, Mary and Lucy as responsible for each clinical site and with one representative of the fellows (to move between them).

To follow up:

- that the educational modules of growth (Mary Limbe and KAW) and DM type 1 (Lucy Mungai and Ragnar Hanås) will be done.
- that there will be a management plan for each diagnose, that will make it possible to calculate costs, need of laboratory tests and of drugs
- strategic plan of the program

Strategic Committee Meeting (SCM)

After half a year, finally a meeting was held in January – see attached protocol. It was a very constructive, inspiring meeting, that if this spirit is kept, there will be an interesting future of the program.

To follow up:

- to schedule SCM every month on the last Wednesday 07.30 at prof Doroty Ngacha's office
- Strategic Plan Day. Promised to have in February – early March
Goal: vision, mission, goals, mile stones, responsibilities; strengthes-weakness; founding for patient costs, founding for the program, team work...
- Kenyan Paediatricians to be informed about the Program
For application 3 (DL 31/3 -09) and 4 (DL 1/8 -09)
Dr Renson Mugwhana and prof Doroty Ngacha to discuss with Ministry of Health to keep payment of some paediatricians for the 6 + 3 months in the program
- Examinations in the program to by structured by prof Doroty Ngacha with the Dean of the University of Nairobi.
Lucy Mungai have got the task to finalize this during Feb/March

Program announcement

There are two more fellow groups that will be trained by tutors from abroad:

3rd: the announcement was sent out with DL 31.3.2009 to the mailing list. Despite all efforts of technical and steering committee some countries have no indicated pediatrician.

4th: ready in order to be sent out 1st week of February with DL 1.8.2009, in time not only for mailing list, but also for advertising in different journals and web sites. To be followed up.

GERTRUD'S

The Gertrud's Garden Children's Hospital has special obligations for the program, since it is where the management regarding office, economy and administration take place. KAW was impressed by the structured way of working at this ISO-9000 certified Children's Hospital, a prize winner due to transparent and sound economy. KAW was also impressed by the leader

skip skills of the CEO, and the professionalism in all parts of the hospital and the personnel in administration and education.

Trustee Meeting:

KAW and the project director Sidney Nesbitt was invited to the January Trustees Meeting in order to raise Awareness of the program as a unique challenge for the hospital

- as a model for

- a) subspecialities in paediatrics
- b) team work
- c) economy: to have all money that comes into the program in a trust to use after need.
(KAW worked together with 4 MTA fellows from Boston, who had this as the goal of a project for Gertrud's as their work for examination, with their Supervisor Professor Anjali Sastry at MIT, working with Paul Farmer and Jim Kim at Harvard.

MEETING, end of January with the CEO at GERTRUD'S

1. The CEO informed about that a new announcement for a skilled project manager is on its way.
2. The CEO promised to equip Gertrud's outpatient clinics, satellites and wellbaby clinics with height and weight equipments.
3. The CEO to be in contact with the Company of the Swedish Growth Charts. (Done, and they will be given for free).
4. Trust for the Program. The CEO asked again Sidney Nesbitt and KAW to come back with a Proposal to the Trustees of Gertrud's at their March meeting.
5. A training Centre at Gertrud's:
A separate building at Gertrud's to accommodate both tutor and fellows, and for education purposes; interestingly this is in the long term plans of Gertrud's.
6. To meet again to follow up all points in April 2009 when KAW will be back in April.

Attachments:

1. Address and Phone numbers
2. Schedule of KAW of January
3. Fellows and Tutor schedule of January
4. Steering Committee Protocol
5. 2 Technical Committee Protocol
6. Trustees meeting, hand outs