SSIEM EDUCATION AND TRAINING COMMITTEE

RECOGNITION OF TRAINING CENTRES FOR PAEDIATRIC METABOLIC MEDICINE

Training Centres.

1. The aim of this process is to establish training centres throughout Europe of a uniform high standard.

2. The process is not intended to be in any way punitive but is intended to ensure the centre can meet the needs of the training programme. It will aim to resolve difficulties and should help to obtain more resources. The criteria will take account of the local set-up. There is no reason why two smaller centres should not combine to offer a training programme with a rotation of trainees.


   a. Application for recognition must come from an appropriate body (preferably national), not from the centres themselves. This is to avoid inappropriate applications. There should also be a letter of support from the Local hospital or University administration (whichever appropriate)

   b. If the application accepted, applicants will then be asked to complete this form. Please be realistic and honest. It is not expected that centres will be able to provide training in all areas in the syllabus but there should be a reasonable balance.

   c. Normally the plan would then be a visit. The composition of the team has to be determined. Based on other specialities it would usually consist of the chairman of the Training Committee, a metabolic specialist from another local centre and a local general paediatrician. The composition of the committee may vary according to local needs. Particular problems may arise in small countries; specialists from a neighbouring one may need to help.

   d. The visit would normally start one afternoon and finish the following day. The documentation would be discussed and interviews held with senior staff, trainees and administrators. This latter may seem surprising but those who have done similar visit have all said it is very helpful. It draws attention to problems and can be a real help to get more resources.

   e. The centre applying for recognition will meet the costs of travel and accommodation.
RECOGNITION OF TRAINING CENTRES FOR PAEDIATRIC METABOLIC MEDICINE (PMM)

DETAILS OF CENTRE(S) SEEKING RECOGNITION

Name of Centre(s)

1. Details of clinical staff.
   a. Permanent/Senior
      i. Name
      ii. Date of appointment to permanent position
      iii. How much time (sessions) is devoted to metabolic medicine?
      iv. Special expertise
   
   A senior member of staff should be nominated to supervise the trainee(s).

   b. Staff in training including Research Fellows (complete details for each
      member of staff)
      i. Duration and structure of appointment
         Overall structure of training period – What other subjects
         are covered? For example neurology, PICU
         Time devoted to PMM.
         How is the PMM time divided between
         Inpatient care, Outpatient clinics, other duties?
         Is there emergency on call commitment - hours/week

2. Details of organisation of work – Please give details of
   a. Departmental timetable. This should include:
      Number of clinics devoted to PMM
      Number of ward rounds. What proportion of time on these is devoted to PMM?
      Details of meetings with dietitians/biochemists/etc

   b. Details of timetable of trainee. This should include
      Details of ward rounds, clinics, on call, genetic counselling, teaching (giving and receiving), presentations and other responsibilities.

3. Workload
   Please list number of:
      In-patients/year.
      Average number at one time and average length of stay
      Out-patients/year
      Day cases/year
      New patients/year (not previously seen by metabolic specialist)
3. Workload (continued)

Referrals from other specialities within hospital/week
NICU
PICU
Other services

Please list number of patients **actively** under the care of the unit (not those seen once or telephone consultation only) in these categories:

<table>
<thead>
<tr>
<th>Intermediary metabolism</th>
<th>for example</th>
<th>PKU</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aminoacid disorders</td>
<td></td>
<td>GSD 1</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td></td>
<td>MMA</td>
</tr>
<tr>
<td>Organic acids</td>
<td></td>
<td>OTC</td>
</tr>
<tr>
<td>Hyperammonaemia</td>
<td></td>
<td>MCAD</td>
</tr>
<tr>
<td>Fatty acid oxidation</td>
<td></td>
<td>Cytochrome oxidase deficiency</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mitochondrial respiratory chain</th>
<th>for example</th>
<th>Hurler</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lysosomal storage disease</td>
<td></td>
<td>Zellweger</td>
</tr>
<tr>
<td>Peroxisomal disorder</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How many patients do you have on continuous feeds?

Does this information reflect your workload?
If not please list the number of most common disorders actively under the clinic

4. Teaching and Research

Do you have departmental meetings?
Do you have an audit programme? Please give brief details
Do you have a research programme? Please give brief details
Please list what you regard as the best 15 publications from your unit in the last 5 years.

5. Hospital Facilities

List the services in your hospital with which you work closely
Paediatric Intensive Care Unit
Neonatal Intensive Care Unit
Neurology
Psychology
Hepatology
Cardiology
Other units with whom your unit works closely if not listed
6. Interface with adults

Is there an adult metabolic service to whom you refer patients with inborn errors?

7. Laboratories

Details of permanent/senior laboratory staff qualifications
area of expertise
time devoted to PMM

Investigations on site

- Ammonia
- Lactate

Aminoacids (quantitative) number/year
Organic acids (GC/MS) number/year
Acyl carnitines number/year

Enzymology give summary of tests done
Molecular genetics give summary of tests done

Do you have a neonatal screening programme attached to your unit
Give tests
Are all the positives seen in your unit?

8. Dietetic services

Do you have dedicated paediatric dietitians
If yes give details
If no who is responsible for dietetics assessment and teaching?

9. Protocols and Guidelines

Do you have written protocols for investigation and management?
Do you provide leaflets with information for primary care doctors and parents

10. Strengths and Weaknesses

What do you think are the strengths and weakness of your unit?

11. Suggestions for improvements

Do you think there are some simple changes, which could improve the service you provide?

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