100th review published!

Tracey Remmington, Managing Editor

I am very pleased to report that on Issue 5, 2011 we published our 100th review!

In addition to the 56 cystic fibrosis reviews we have published, we have 27 in haemoglobinopathies, 11 in inborn errors of metabolism, 2 in coagulaopthies, and 4 ‘orphan’ reviews (reviews not directly under our Group’s scope).

We look forward to increasing our output in the future across all areas of the Group’s scope and to receiving many, many new title registration forms from review authors all over the world!

If you, or your colleagues, are interested in registering a new review title, then please do not hesitate to contact the Group. We do have a list of priority reviews which can be found at: http://cfgd.cochrane.org/reviews-needed. We look forward to hearing from you!

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The Cochrane Collaboration now a Non-Governmental Organization with the WHO

Nikki Jahnke
Asst Managing Editor

The Cochrane Collaboration Steering Group was recently delighted to announce that the Collaboration has been accepted as a Non-Governmental Organization in Official Relations with the World Health Organization (WHO) at the WHO’s Executive Board meeting in Geneva, Switzerland. In formalizing the its relationship with the WHO, the Cochrane Collaboration has been awarded a seat at the World Health Assembly, allowing it to provide input on WHO health resolutions.

The World Health Assembly is the decision-making body of WHO. It is attended by delegations from all WHO Member States and focuses on a specific health agenda prepared by the Executive Board. The main functions of the World Health Assembly are to determine the policies of the Organization, appoint the Director-General, supervise financial policies, and review and approve the proposed programme budget. The Health Assembly is held annually in Geneva, Switzerland and the next meeting is in May 2011.

"Formulating an official partnership with an influential institute such as the World Health Organization is an honour. This speaks volumes about the work of Cochrane in evidence-based health care," says Jeremy Grimshaw, Co-Chair of the Steering Group. Marie-Paule Kieny, Assistant Director General, Innovation Information Evidence and Research at the World Health Organization added "The Cochrane Collaboration provides an international benchmark for the independent assessment and assimilation of scientific evidence. It is a leading producer of high quality systematic reviews in health care. WHO has been working with The Cochrane Collaboration for several years and is looking forward to formalizing what has already been a very productive relationship."

Spreading the Cochrane message in the 21st century

Nikki Jahnke
Asst Managing Editor

Claire Glenton and Sarah Rosenbaum from the Nordic Cochrane Centre’s Norwegian Branch have made a video presenting the results of a Cochrane review on lay health workers for mother and child health and infectious diseases (Lewin et al, 2010). The information is based on the Summary of Findings table/Plain Language Summary/SUPPORT summary of the review. The programme they used also allows for subtitles in another language (but this function has not yet been included). Ultimately, they would like to develop a format that works and can be used for other Cochrane reviews. The main target group for the video is policy makers in low and middle income countries, and they plan to carry out user tests among this group at a later stage. Until then, they will be collecting comments and welcome all feedback. The video is posted on YouTube:

http://www.youtube.com/watch?v=0zHHhpE5Rb0

Comments can be sent via YouTube or directly to Claire Glenton (Claire.glenton@nokc.no)
The annual UK Cochrane Contributors Meeting took place in Belfast in March. As always this meeting provided a chance for UK-based members of the Collaboration to meet and exchange ideas.

The first plenary session showed the importance and impact of Cochrane on the island of Ireland. There is a unique scheme in place there which is funded by the Health Research Board in Eire and the Department of Health, Social Services and Public Safety in Northern Ireland. This scheme allows successful candidates to work for 2 days per week for 2 years on a Cochrane review and its aim is to increase the capacity for undertaking, understanding and using systematic reviews and to produce reviews that are of relevance to the island of Ireland. Its success speaks for itself – 39 recipients from 2002 to 2008 have so far published 26 full reviews and a further 9 protocols have been published which are progressing to full publication.

The second plenary focussed on Cochrane reviews from different perspectives. We heard how the publishers are working to increase the impact of our published reviews through the media and collaboration with policy makers. There were also short presentations on what consumers want from reviews, the effect advancements in systematic review methodology is having on what is expected of authors and in turn, what The Cochrane Collaboration is doing to support authors.

There were a wide range of workshops on offer ranging from hands-on software sessions looking at the new release of RevMan (see page 4) and the latest modules of the online learning resource. There were also workshops on searching and the latest developments of the new Central Register of Studies (a beta version is due to be released in the summer with a full launch scheduled for the Colloquium in October). Methodological sessions covered issues such as the generation of core outcome sets for trials and reviews, risk of bias assessments, assessing and dealing with heterogeneity and using GRADE software to produce Summary of Findings tables. Less technical sessions covered topics such as podcasting for authors and prioritising new reviews and updates.

An interesting article ……

**Interpretation of random effects meta-analyses**
Richard D Riley, Julian P T Higgins, Jonathan J Deeks
*BMJ 2011;342:doi:10.1136/bmj.d549 (Published 10 February 2011)*
Release of RevMan 5.1

Nikki Jahnke  
Asst Managing Editor

The latest version of RevMan (RevMan 5.1) was released at the end of March. The new version was developed in response to feedback from authors and other users. We strongly recommend that you update to RevMan 5.1, if you are prompted to update automatically next time you open RevMan, please accept - the updating process should only take a few minutes.

There are several reasons why you should update the software:
• The update includes many new improved features that will make it easier for you to complete your review, see http://ims.cochrane.org/revman/documentation/RevMan-5.1-whatsnew.pdf for details.
• There are modifications and improvements to the Risk of Bias tool in RevMan 5.1, which can only be viewed in RevMan 5.1.
• Using the same version as the editorial base of your Review Group will ease the process of submitting new or updated reviews for publication (although authors will not be required to update to RevMan 5.1, editorial bases must update).

You will find other updated support materials in the RevMan 5.1 Help menu, such as the Handbook, RevMan User Guide and tutorials. The new version 5.1.0 of the Cochrane Handbook for Systematic Reviews of Interventions is also available online at http://www.cochrane.org/training/cochrane-handbook.

19th Cochrane Colloquium  
19 – 22 October 2011, Madrid

The 19th Cochrane Colloquium is being hosted by the Iberoamerican Cochrane Centre at the Palacio de Congresos de Madrid. The theme of the 19th Cochrane Colloquium is "Scientific evidence for healthcare quality and patient safety". This provides a good opportunity to celebrate the Colloquium in conjunction with the VI International Conference on Patient Safety, organised by the National Agency for Health Care Quality at the Spanish Ministry of Health. It is time for the Collaboration to reflect on and analyse its possible contributions to the improvement of the quality of care and safety of patients. These are now very real priorities for the World Health Organization, governments, healthcare institutions and professionals all over the world.

In addition to the issues more directly related to health quality and patient safety, there will be many opportunities to learn together and to discuss a large variety of methodological issues and topics of great interest, directed to the usual participants as well as to newcomers.

Finally, the city itself! Madrid offers many options for enjoying its culture, music and food - life in all of its expressions! Don't miss this opportunity and you will be happy with your decision. For further information and deadlines, please visit the colloquium website at: http://colloquium.cochrane.org/
Abstract

Background
Inhalation of the enzyme dornase alfa reduces sputum viscosity and improves clinical outcomes of people with cystic fibrosis.

Objectives
To determine the effect of timing of dornase alfa inhalation on measures of clinical efficacy in people with cystic fibrosis (in relation to airway clearance techniques or time of day).

Search strategy
Relevant randomised and quasi-randomised controlled trials were identified from the Cochrane Cystic Fibrosis Trials Register, Physiotherapy Evidence Database (PEDro), and international CF conference proceedings.

Search date: 6 October 2010.

Selection criteria
Any trial of dornase alfa in people with cystic fibrosis where timing of inhalation was the randomised element in the study with either: inhalation before compared to after airway clearance techniques; or morning compared to evening inhalation.

Data collection & analysis
Both authors independently selected trials, assessed risk of bias and extracted data with disagreements resolved by discussion. Relevant data were extracted and, where possible, meta-analysed.

Main results
We identified 92 trial reports representing 47 studies, of which five studies (providing data on 122 participants) met our inclusion criteria. All five studies used a cross-over design. Intervention periods ranged from two to eight weeks. Four trials compared dornase alfa inhalation before versus after airway clearance techniques. Inhalation after instead of before airway clearance did not significantly change FEV$_1$. Similarly, FVC and quality of life were not significantly affected; FEF$_{25}$ was significantly worse with dornase alfa inhalation after airway clearance, MD -0.17 litres (95% CI -0.28 to -0.05), based on the pooled data from two small studies in children (7 to 19 years) with well-preserved lung function. All other secondary outcomes were statistically non-significant.

In one trial, morning versus evening inhalation had no impact on lung function or symptoms.

Authors’ conclusions
The current evidence derived from a small number of participants does not indicate that inhalation of dornase alfa after airway clearance techniques is more or less effective than the traditional recommendation to inhale nebulised dornase alfa 30 minutes prior to airway clearance techniques, for most outcomes. For children with well-preserved lung function, inhalation before airway clearance may be more beneficial for small airway function than inhalation after. However, this result relied on a measure with high variability and studies with variable follow-up. Apart from this, the timing of dornase alfa inhalation can be largely based on pragmatic reasons or individual preference with respect to the time of airway clearance and time of day. Further research is warranted.
Abstract

Background
Nasal polyps frequently occur in people with cystic fibrosis. Sinus infections have been shown to be a factor in the development of serious chest complications in these people. Nasal polyps have been linked to a higher risk of lower respiratory tract infections with Pseudomonas aeruginosa. Topical nasal steroids are of proven efficacy for treating nasal polyposis in the non-cystic fibrosis population. There is no clear current evidence for the efficacy of topical steroids for nasal polyps in people with cystic fibrosis.

Objectives
To assess the effectiveness of topical nasal steroids for treating symptomatic nasal polyps in people with cystic fibrosis.

Search strategy
We searched the Cochrane Cystic Fibrosis and Genetic Disorders Group Trials Register comprising references identified from comprehensive electronic database searches and handsearches of relevant journals and abstract books of conference proceedings. Latest search: 02 February 2011.

Selection criteria
Randomised and quasi-randomised controlled comparing the effects of topical nasal steroids to placebo in people with nasal polyps with cystic fibrosis.

Data collection & analysis
Two authors independently assessed risk of bias in the included trial and extracted data.

Main results
One single-centred trial (46 participants) was identified comparing a topical steroid (betamethasone) to placebo. Twenty-two participants received the active drug. Subjective symptom scores, change in polyp size, and side effects were assessed. There was no difference in nasal symptom scores between the treatment and placebo groups. Betamethasone was effective in reducing the size of polyps, but was associated with increased reports of mild side effects, nasal bleeding and discomfort. Risk of bias was high since over 50% of people enrolled did not complete the study. Follow-up of patients was short (six weeks) also reducing the significance of the results for clinical practice.

Authors' conclusions
This review suggests topical steroids for nasal polyposis in patients with cystic fibrosis have no demonstrable effect on subjective nasal symptom scores. They have some effect in reducing the size of the polyps, but due to the small sample size, poor study completion rates and lack of follow-up, the study is at high risk of bias and evidence for efficacy is limited. Overall there is no clear evidence for using topical steroids in people with cystic fibrosis and nasal polyposis.

A well-designed randomised controlled trial of adequate power and long-term follow-up is needed. Validated measures of symptoms and physical findings should be performed and quality of life issues addressed.
### 2011 Timetable for Cochrane Workshops

#### Asia-Pacific Region Workshops

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<tr>
<th>Date</th>
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<tbody>
<tr>
<td>30 – 31 May 2011</td>
<td>Kelantan</td>
<td>Introduction to writing a Cochrane Review</td>
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<tr>
<td>04 – 08 July 2011</td>
<td>Kuala Lumpur</td>
<td>Developing a protocol for a Cochrane Systematic Review</td>
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#### Australasian Cochrane Centre

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<tr>
<th>Date</th>
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<tr>
<td>06 – 07 June 2011</td>
<td>Gold Coast</td>
<td>Introduction to writing a Cochrane Review</td>
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<tr>
<td>07 – 08 July 2011</td>
<td>Sydney</td>
<td>Introduction to writing a Cochrane Review</td>
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<tr>
<td>11 – 12 August 2011</td>
<td>Adelaide</td>
<td>Introduction to writing a Cochrane Review</td>
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#### Brazilian Cochrane Centre
For more information see: [http://www.centrocochranedobrasil.org.br/](http://www.centrocochranedobrasil.org.br/)

#### Canadian Cochrane Centre

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<tr>
<td>27 – 28 May 2011</td>
<td>Hamilton, Ontario</td>
<td>Cochrane Standard Author Training</td>
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#### Dutch Cochrane Centre

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<tr>
<td>17 May 2011</td>
<td>Amsterdam</td>
<td>Development of a systematic review</td>
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#### German Cochrane Centre

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<th>Date</th>
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<tr>
<td>30 June – 01 July 2011</td>
<td>Berlin, Germany</td>
<td>Methods Training Event 2011</td>
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<tr>
<td>04 – 08 July 2011</td>
<td>Krems, Austria</td>
<td>Workshop on systematic reviews</td>
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#### Iberoamerican Cochrane Centre
For more information see: [http://www.cochrane.es/](http://www.cochrane.es/)

#### Nordic Cochrane Centre
For more information see: [http://www.cochrane.dk/courses/index.htm](http://www.cochrane.dk/courses/index.htm)

#### South African Cochrane Centre

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<td>30 May – 03 June 2011</td>
<td>Cape Town</td>
<td>Cochrane Review protocol development and RevMan workshop</td>
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#### UK Cochrane Centre

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<td>Nottingham</td>
<td>Systematic Review Course</td>
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#### US Cochrane Centre

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<tr>
<td>13 – 15 July 2011</td>
<td>Baltimore</td>
<td>Completing a Cochrane Systematic Review Workshop</td>
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Cochrane Centres

Centres share a responsibility for helping to co-ordinate and support the Cochrane Collaboration. The shared responsibility of the Cochrane Centres includes organising workshops, seminars and colloquia to support and guide the development of the Cochrane Collaboration.

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PEOPLE’S REPUBLIC OF CHINA
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http://www.ebm.org.cn

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Johns Hopkins Bloomberg School of Public Health
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Baltimore Maryland 21205
USA
E-mail: uscc@jhsph.edu
http://www.us.cochrane.org
Please photocopy, complete and return the following section if:

- Your contact details have changed & you wish to be kept informed about the Cystic Fibrosis and Genetic Disorders Group
- You are not on our mailing list and you would like to receive information about the Group in the future
- You would like to be removed from the Group’s mailing list

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**Proposed contribution to Cystic Fibrosis and Genetic Disorders Group, if any (e.g. undertaking a review (give interested area), hand searching, refereeing, etc):**

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<th>I would like to receive future postal mailings: Yes / No</th>
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Trial Registers

The register of randomised controlled trials (RCTs) for **cystic fibrosis** contains 1823 references to 1089 RCTs. This is compiled from electronic searches of the Cochrane Central Register of Controlled Trials (updated each new issue), quarterly searches of MEDLINE, a search of EMBASE to 1995 and the prospective handsearching of two journals: *Pediatric Pulmonology*; and the *Journal of Cystic Fibrosis*. Unpublished work is identified by searching the abstract books of three major cystic fibrosis conferences: the International Cystic Fibrosis Conference; the European Cystic Fibrosis Conference and the North American Cystic Fibrosis Conference.

The **haemoglobinopathies** register holds 613 references to 323 trials, the **coagulopathies** register has 276 references to 191 trials, and there are also 146 references for **phenylketonuria** and 658 references for **hyperlipoproteinaemia** (subsets on the **inborn errors of metabolism** register). As well as the electronic searching described above the following are searched for trials to include in the genetic disorders registers: the journals: *Haemophilia* and the *Journal of Inherited Metabolic Disease*; and the proceedings of the European Haematology Association conference; the American Society of Hematology conference; the Caribbean Health Research Council Meetings; the National Sickle Cell Disease Program Annual Meeting; the European Haematology Association conference; the American Society of Hematology conference; and the Society for the Study of Inborn Errors of Metabolism conference.
Cystic fibrosis reviews
Active cycle of breathing technique for cystic fibrosis
Antibiotic adjuvant therapy for pulmonary infection in cystic fibrosis
Antibiotic strategies for eradicating Pseudomonas aeruginosa in people with cystic fibrosis
Antifungal therapies for allergic bronchopulmonary aspergillosis in people with cystic fibrosis
Anti-inflammatory drugs and analgesics for managing symptoms in people with cystic fibrosis -related arthritis
Antioxidant micronutrients for inflammation and oxidation in cystic fibrosis lung disease
Bisphosphonates for osteoporosis in people with cystic fibrosis
Chemical pleurodysis versus surgical intervention for persistent and recurrent pneumothoraces in cystic fibrosis
Chest physiotherapy compared to no chest physiotherapy for cystic fibrosis
Combination antimicrobial susceptibility testing for acute exacerbations in chronic infection of Pseudomonas aeruginosa in cystic fibrosis
Conventional chest physiotherapy compared to any form of chest physiotherapy for cystic fibrosis
Disease modifying anti-rheumatic drugs in people with cystic fibrosis -related arthritis
Dornase alfa for cystic fibrosis
Drug therapies for reducing gastric acidity in cystic fibrosis
Duration of IV antibiotic therapy for people with cystic fibrosis
Elective versus symptomatic intravenous antibiotic therapy for cystic fibrosis
Enteral tube feeding for cystic fibrosis
Home intravenous antibiotics for cystic fibrosis
Inhaled bronchodilators for cystic fibrosis
Inhaled corticosteroids for cystic fibrosis
Inspiratory muscle training for cystic fibrosis
Insulin and oral agents for managing cystic fibrosis-related diabetes
Macrolide antibiotics for cystic fibrosis
Nebulized and oral thiol derivatives for pulmonary disease in cystic fibrosis
Nebulised anti-pseudomonal antibiotic therapy for cystic fibrosis
Nebulised hypertonic saline for cystic fibrosis
Neuraminidase inhibitors for the treatment of influenza infection in people with cystic fibrosis
Newborn screening for cystic fibrosis
Non-invasive ventilation for cystic fibrosis
Omega-3 fatty acids for cystic fibrosis
Once daily versus multiple daily dosing with intravenous aminoglycosides for cystic fibrosis
Oral anti-pseudomonal antibiotics for cystic fibrosis
Oral calorie supplements for cystic fibrosis
Oral non-steroidal anti-inflammatory drugs for cystic fibrosis
Oral steroids for cystic fibrosis
Oscillating devices for airway clearance in people with CF
Oxygen therapy for cystic fibrosis
Palivizumab for prophylaxis against respiratory syncytial virus infection in children with cystic fibrosis
PEP physiotherapy for airway clearance in cystic fibrosis
Percutaneous long lines for administering intravenous antibiotics in people with cystic fibrosis
Physical training for cystic fibrosis
Prophylactic anti-staphylococcal antibiotics for cystic fibrosis
Psychological interventions for people with cystic fibrosis and their families
Singing for children and adults with cystic fibrosis
Single versus combination intravenous antibiotic therapy for people with cystic fibrosis
Sodium channel blockers for cystic fibrosis
Timing of dornase alfa inhalation for cystic fibrosis
Topical cystic fibrosis transmembrane conductance regulator gene replacement for CF-related lung disease
Topical nasal steroids for treating nasal polyposis in people with cystic fibrosis
Totally implantable vascular access devices for cystic fibrosis
Ursodeoxycholic acid for cystic fibrosis -related liver disease
Vaccines for preventing infection with Pseudomonas aeruginosa in people with cystic fibrosis
Vaccines for preventing influenza in people with cystic fibrosis
Vitamin A supplementation for CF
Vitamin D supplementation for cystic fibrosis
Vitamin K supplementation for cystic fibrosis

Cochrane Cystic Fibrosis and Genetic Disorders Review Group

http://www.wileyeurope.com/go/cochrane
Cystic fibrosis protocols
Appetite stimulants for people with cystic fibrosis
Inhaled antibiotics for pulmonary exacerbations in people with cystic fibrosis
Inhaled mannitol for cystic fibrosis
Nebuliser devices for drug delivery in cystic fibrosis
Pancreatic enzyme replacement therapy for people with cystic fibrosis
Pneumococcal vaccines for cystic fibrosis
Recombinant growth hormone therapy for children and young adults with cystic fibrosis
Self-management education for cystic fibrosis
Timing of hypertonic saline inhalation in cystic fibrosis

Haemoglobinopathy reviews
Antibiotics for treating acute chest syndrome in people with sickle cell disease
Antibiotics for treating community acquired pneumonia in people with sickle cell disease
Antibiotics for treating osteomyelitis in people with sickle cell disease
Blood transfusion for acute chest syndrome in people with sickle cell disease
Blood transfusion for preventing stroke in people with sickle cell disease
Deferasirox for iron chelation in people with transfusion-dependent sickle cell disease
Desferrioxamine mesylate for managing transfusional iron overload in people with transfusion-dependent thalassaemia
Drugs for preventing red blood cell dehydration in people with sickle cell disease
Fluid replacement therapy for acute episodes of pain in people with sickle cell disease
Gene therapy for sickle cell disease
Hematopoietic stem cell transplantation for children with sickle cell disease
Hydroxyurea for sickle cell disease
Inhaled bronchodilators for acute chest syndrome in people with sickle cell disease
Inhaled nitric oxide for treating acute chest syndrome in people with sickle cell disease
Neonatal screening for sickle cell disease
Oral deferiprone for iron chelation in people with thalassaemia
Phytotherapies (medicines derived from plants) for sickle cell disease
Piracetam for reducing the incidence of sickle cell disease crises
Pneumococcal vaccines for sickle cell disease
Preoperative blood transfusions for sickle cell disease
Prophylactic antibiotics for preventing pneumococcal infection in children with sickle cell disease
Psychological therapies to sickle cell disease and pain
Psychological therapies for thalassaemia
Splenectomy versus conservative management for acute sequestration crises in people with sickle cell disease
Treatment for avascular necrosis of bone in people with sickle cell disease
Treatments for priapism in boys and men with sickle cell disease
Vaccines for preventing invasive salmonella infections in people with sickle cell disease

Haemoglobinopathy protocols
Deferasirox for iron chelation in people with transfusion-dependent thalassaemia
Interventions for treating leg ulcers in people with sickle cell disease
Regular long-term red blood cell transfusions for chronic chest complications in people with sickle cell disease
Stem cell transplantation for people with beta thalassaemia major
Coagulopathy reviews
Clotting factor concentrates given to prevent bleeding and bleeding-related complications in people with hemophilia A or B
Recombinant Factor VIIa concentrate versus plasma derived concentrates for the acute treatment of Haemophilia A & inhibitors

Inborn errors of metabolism reviews
Bisphosphonate therapy for osteogenesis imperfecta
Carnitine supplementation for the treatment of inborn errors of metabolism
Dietary interventions for phenylketonuria
Dietary treatment for familial hypercholesterolaemia
Enzyme replacement therapy for Fabry disease
Hematopoietic stem cell transplantation for Gaucher disease
Intravenous alpha-1 antitrypsin augmentation therapy for treating patients with alpha-1 antitrypsin deficiency and lung disease
Protein substitute for children and adults with phenylketonuria
Recombinant growth hormone therapy for X-linked hypophosphatemia in children
Sapropterin dihydrochloride for phenylketonuria
Statins for familial hypercholesterolemia in children
Tyrosine supplementation in phenylketonuria

Inborn errors of metabolism protocols
Enzyme replacement therapy with idursulfase for mucopolysaccharidosis type II (Hunter syndrome)
Newborn screening for homocystinuria

Orphan reviews
Dietary advice for illness-related malnutrition in adults
Embolisation therapy for pulmonary arteriovenous malformations
Oral protein calorie supplementation for children with chronic disease

Orphan protocols
Proanthocyanidin supplements for the treatment of chronic disorders
Surgical interventions for treating pectus excavatum