Editorial
Feedback on the Group

Tracey Remmington, Managing Editor

We are very pleased to have recently received some additional metrics from the Cochrane Editorial Unit that have helped us reflect on our workload and performance.

In reference to review production, we were 8th out of 53 Cochrane groups from 2008 to 2010. For the same period we were 2nd in the number of updated and split reviews produced and 2nd lowest in the time elapsed between publication of protocol and full review.

We would like to take this opportunity to thank all of our Group’s contributors who all work so hard to produce our protocols, reviews and update.

Online usage of our reviews
Wiley have also provided us with some usage data. Our reviews were accessed in full-text format on average 361.74 times during 2010 (100 articles accessed 36,174 times). This is an increase of 14% on the 2009 figure of 310.98 (97 articles accessed 30,165 times).

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Output of the CFGD Group
105 reviews & 19 protocols published on Issue 11 2011 of The Cochrane Library
Impact factor 2010 for the Cochrane Database of Systematic Reviews

Nikki Jahnke
Asst Managing Editor

In June the 2010 Journal Citation Report (JCR) was released by Thomson ISI. This includes the Impact Factors for a number of journals, amongst them The Cochrane Database of Systematic Reviews (CDSR). The Impact Factor is a tool for ranking, evaluating, and comparing journals. It is a measure of the frequency with which the “average article” in a journal has been cited in a particular year. The Impact Factor for 2010 is calculated by dividing the number of citations in 2010 to the number of reviews published in that journal during the previous two years (2008 and 2009).

The 2010 Impact Factor for the CDSR is 6.186.

Some highlights of the 2010 Impact Factor include:
• This is an increase on the 2009 Impact Factor which was 5.653 and the 4th consecutive year that the CDSR Impact Factor has increased.
• The CDSR is now ranked in the top 10 of the 151 in the Medicine, General & Internal category.
• The total number of times the CDSR was cited increased from 23,102 in 2009 to 27,366 meaning the CDSR receives the 7th highest number of citations in its category.

Review authors can use the ISI Web of Science (www.isiknowledge.com/; subscription required) to track citations to their reviews. However, since ISI have difficulty matching some citations to the original Cochrane Review, the number of citations shown may not be a true representation of all citations for an individual review – in most cases it will be an underestimate of the total citations. Our publishers (Wiley-Blackwell) are working with ISI to identify these cases and to allocate these citations back to the original reviews. To avoid this issue, authors should always reference Cochrane Reviews correctly using the “this record should be cited as” guidance in the header of each review article.

While the improved Impact Factor is excellent news, it should also be remembered that Cochrane Reviews have a much wider impact than can be measured by citations alone. Other examples of impact include informing guideline development, policy setting, consumer communication and many others in order to inform and improve healthcare decision-making.

Podcasts

Tracey Remmington
Managing Editor

We are keen to encourage authors to record a podcast describing the findings of their review, which will appear on The Cochrane Library homepage. This is an exciting way to promote your review and the Cochrane CFGD Group welcomes any author wishing to take advantage of this opportunity. Currently, most podcasts are in English, but authors are encouraged to record a podcast in any language. For a guide to creating a podcast for The Cochrane Library please visit: http://www.cochrane.org/multimedia/podcasts/guide-podcasting.

This guide gives an introduction to Podcasting and then shows you how to record audio and put it online as a podcast, using tools freely available on the web. Please do contact Nikki Jahnke (nikkij@liv.ac.uk) or myself (traceyr@liv.ac.uk) if you do plan on recording a podcast or for further information on this opportunity.
Free access to all data from clinical trials

Nikki Jahnke
Asst Managing Editor

The issue of selective outcome reporting and non-publication of trial data has been widely highlighted in recent years by The Cochrane Collaboration. Internally, the Collaboration has encouraged review authors to consider this by incorporating an assessment of the risk of bias from missing data and from selective reporting within the trials which they have included in their reviews. Authors are asked to comment on the extent of both these issues how they may affect the results presented in the review. The CFGD Group’s own medical statistician, Dr Kerry Dwan, was involved in the ORBIT (Outcome Reporting Bias In Trials) project (see http://www.liv.ac.uk/nwhtmr/orbit/ORBIT.htm). She is currently carrying this work forward to currently look at the extent of this problem in the intervention reviews for cystic fibrosis which the CFGD Group has published and we hope to have some firm conclusions to present early next year.

Outcome reporting bias has been defined as the selection for publication of a subset of the original recorded outcome variables based on the results. The ORBIT project found that a third of Cochrane reviews analysed contained at least one trial with a high suspicion of ORB for the review’s primary outcome; in many cases investigators in the trials included in these reviews were found to have reported the outcomes in a biased way; and few guidelines from trial funders referred to the importance of publishing negative as well as positive findings, while none referred explicitly to the need to report results for all outcomes that were analysed.

Many organisations, such as the WHO, the US National Institutes of Health and the European Commission, have called for all research data to be shared. The Cochrane Collaboration has just published a statement about access to clinical trial data (http://www.cochrane.org/about-us/our-policies/support-free-access-to-all-data-from-all-clinical-trials).

The failure to make all clinical trial data available is a potential threat to evidence-based medicine as it may lead to incorrect decisions concerning effective healthcare. There are many cases where the beneficial effects of healthcare interventions have been exaggerated and their harms underestimated, often quite considerably. This problem is currently discussed in an editorial by one of our review authors, Prof Peter Gotzsche, on The Cochrane Library (http://www.thecochranelibrary.com/details/editorial/1359903/We-need-access-to-all-data-from-all-clinical-trials.html).

While the European Medicines Agency (EMA) is now committed to providing access to clinical study reports and corresponding trial protocols, access to other data held by both national agencies across the globe and by pharmaceutical companies may still be difficult at best, if not impossible. Making trial data freely available is vital for a number of reasons, but principally to provide decision makers with better information about the true benefits and harms of interventions and to save both researchers and patients from duplication of effort within the research framework.

An interesting article ……

Meta-analyses of adverse effects data derived from randomised controlled trials as compared to observational studies: methodological overview.
Golder S, Loke YK, Bland M.
The 19th Cochrane Colloquium was held in junction with the VI International Conference on Patient Safety. The theme for the conference was ‘Scientific evidence for healthcare quality and patient safety’.

The opening session was titled ‘Global collaborations and health alliances’. Other plenary sessions included ‘Interventions to reduce adverse events impact on health care’, ‘Using evidence to improve health systems’, ‘Implementing the evidence into the system’, “The challenges of reviewing science in the XXI century’ and ‘Designing a sustainable evidence-based health care in times of crisis’. The full scientific programme can be found at: http://colloquium.cochrane.org/scientific-programme.

Kerry Dwan, the CFGD Group’s statistician won an award for the most accessed methodological podcast (www.cochrane.org/podcasts/international-clinical-trials-day-2011/changes-between-protocols-and-reports).

The Chris Silagy Prize for an “extraordinary” contribution to the work of The Cochrane Collaboration was awarded jointly to Martin Janczyk (The Cochrane Web Team) and Juliane Ried who has been involved in organizing several of the recent colloquia and is now a member of the Cochrane Innovations Team.

The next Cochrane Colloquium is due to be held in 2012 in China. Further details will be made available as soon as possible.

Cochrane Reviews influence clinical guidelines

Tracey Remmington & Nikki Jahnke
Managing Editors

As already mentioned on page 2, Cochrane Reviews are influential; not only are they regularly cited in other journal articles, they are also widely cited in national clinical guidelines. A recent editorial specifically discussed the use of Cochrane Reviews in UK National Institute for Clinical Excellence (NICE) guidelines: http://www.thecochranelibrary.com/details/editorial/1312103/The-use-of-Cochrane-Reviews-in-NICE-clinical-guidelines.html. Cochrane Reviews are cited in over 80% of NICE guidelines, with some reviews being cited in more than one set of guidelines. Of the 52 registered Cochrane Review Groups, 46 had reviews cited in NICE guidelines.

Directly relevant to our Group, one of these NICE guidelines cites the CFGD Group’s review of dietary treatment for familial hypercholesterolaemia. Furthermore, many of our CF reviews are cited in several sets of guidelines and consensus documents from the UK, Europe, USA and Australasia. Several of our haemoglobinopathy reviews are used in UK and Australian guidelines for treating sickle cell disease and thalassaemia; and one of our haemophilia reviews is cited in a guideline published by the Haemophilia Centre Doctors’ Organization the UK.

Although it is apparent that there is widespread use of Cochrane Reviews in clinical guidelines, there is no doubt that they could be used more efficiently by involvement of Cochrane Review authors in guideline development groups. Cochrane Reviews and guideline questions should be better aligned and knowledge from Cochrane Reviews should be shared with those developing guidelines. Speed in turning relevant Cochrane Protocols into Cochrane Reviews, or updating Cochrane Reviews, so that they can be considered for a clinical guideline is important. It is not easy to convert non-Cochrane Reviews into Cochrane Reviews, but if Cochrane and guideline developers’ different timelines and processes could work together, it should reduce duplication of effort.
Self-management education for cystic fibrosis

Reviewers: Savage E, Beirne PV, Ni Chroinin M, Duff A, Fitzgerald T, Farrell D

Abstract

Background

Self-management education may help patients with cystic fibrosis and their families to choose, monitor and adjust treatment requirements for their illness, and also to manage the effects of illness on their lives. Although self-management education interventions have been developed for cystic fibrosis, no previous systematic review of the evidence of effectiveness of these interventions has been conducted.

Objectives

To assess the effects of self-management education interventions on improving health outcomes for patients with cystic fibrosis and their caregivers

Search strategy

We searched the Cochrane Cystic Fibrosis and Genetic Disorders Group Trials Register (date of the last search: 23 February 2011).

We also searched databases through EBSCO (CINAHL; Psychological and Behavioural Sciences Collection; PsychInfo; SocINDEX) and Elsevier (EMBASE) and handsearched relevant journals and conference proceedings (date of the last searches: 30th March 2011).

Selection criteria

Randomised controlled trials, quasi-randomised controlled trials or controlled clinical trials comparing different types of self-management education for cystic fibrosis or comparing self-management education with standard care or no intervention.

Data collection & analysis

Two authors assessed trial eligibility and risk of bias. Three authors extracted data.

Main results

Four trials (involving a total of 269 participants) were included. The participants were children with cystic fibrosis and their parents or caregivers in three trials and adults with cystic fibrosis in one trial. The trials compared four different self-management education interventions versus standard treatment: (1) a training programme for managing cystic fibrosis in general; (2) education specific to aerosol and airway clearance treatments; (3) disease-specific nutrition education; and (4) general and disease-specific nutrition education. Training children to manage cystic fibrosis in general had no statistically significant effects on weight after six to eight weeks, mean difference -7.74 kg (95% confidence interval -35.18 to 19.70). General and disease-specific nutrition education for adults had no statistically significant effects on: pulmonary function (forced expiratory volume at one second), mean difference -5.00 % (95% confidence interval -18.10 to 8.10) at six months and mean difference -5.50 % (95% confidence interval -18.46 to 7.46) at 12 months; or weight, mean difference -0.70 kg (95% confidence interval -6.58 to 5.18) at six months and mean difference -0.70 kg (95% confidence interval -6.62 to 5.22) at 12 months; or dietary fat intake scores, mean difference 1.60 (95% confidence interval -2.90 to 6.10) at six months and mean difference 0.20 (95% confidence interval -4.08 to 4.48) at 12 months. There is some limited evidence to suggest that self-management education may improve knowledge in patients with cystic fibrosis but not in parents or caregivers. There is also some limited evidence to suggest that self-management education may result in positively changing a small number of behaviours in both patients and caregivers.

Authors' conclusions

The available evidence from this review is of insufficient quantity and quality to draw any firm conclusions about the effects of self-management education for cystic fibrosis. Further trials are needed to investigate the effects of self-management education on a range of clinical and behavioural outcomes in children, adolescents and adults with cystic fibrosis and their caregivers.
New review – Issue 8, 2011

Newborn screening for homocystinuria

Reviewers: Walter JH, Jahnke N, Remmington T

Abstract

Background
Homocystinuria is a rare inherited disorder due to a deficiency in cystathionine beta synthase. Individuals with this condition appear normal at birth but develop serious complications in childhood. Diagnosis and treatment started sufficiently early in life can effectively prevent or reduce the severity of these complications.

Objectives
To determine if newborn population screening for the diagnosis of homocystinuria due to cystathionine beta synthase deficiency leads to clinical benefit compared to later clinical diagnosis.

Search strategy
We searched the Cochrane Cystic Fibrosis and Genetic Disorders Group's Inborn Errors of Metabolism Trials Register.
Date of the most recent search of the Inborn Errors of Metabolism Register: 27 June 2011.

Selection criteria
Randomised controlled trials and controlled clinical trials assessing the use of any neonatal screening test to diagnose infants with homocystinuria before the condition becomes clinically evident. Eligible studies compare a screened population versus a non-screened population.

Data collection & analysis
No studies were identified for inclusion in the review.

Main results
No studies were identified for inclusion in the review.

Authors' conclusions
We were unable to identify eligible studies for inclusion in this review and hence it is not possible to draw any conclusions based on controlled studies; however, we are aware of uncontrolled case-series which support the efficacy of newborn screening for homocystinuria and its early treatment. Any future randomised controlled trial would need to be both multicentre and long term in order to provide robust evidence for or against screening and to allow a cost effectiveness analysis to be undertaken.
Reviewers: Cho G, Hambleton IR

Abstract

Background
Sickle cell disease can cause severe vaso-occlusive crises and dysfunction of most organ systems. The two most common chronic chest complications due to sickle cell disease are pulmonary hypertension and chronic sickle lung disease. These complications can lead to morbidity (such as reduced exercise tolerance) and increased mortality.

Objectives
The aim of this review is to find out whether trials involving people with sickle cell disease that compare regular long-term blood transfusion regimens with an alternative treatment or no treatment show differences in the following:
1. the incidence of chronic chest complications (chronic sickle lung disease or pulmonary hypertension);
2. the ‘severity’ or progression of established chronic chest complications;
3. the mortality associated with chronic chest complications; and
4. unacceptable adverse events.

Search strategy
We searched the Group’s Haemoglobinopathies Trials Register. Specific websites were also searched for information of ongoing or newly completed trials. The search included the reference lists of any randomised controlled trials identified using the above methods.

Date of the most recent search of the Cochrane Cystic Fibrosis and Genetic Disorders Group's Haemoglobinopathies Trials Register: 18 April 2011.

Selection criteria
We included randomized controlled trials. Trials that used quasi-randomized methods were to be included if sufficient evidence existed that the treatment and control groups were similar at baseline. Trials were eligible for inclusion if they investigated regular red blood cell transfusion regimens (either simple top-up or exchange transfusions) aimed at reducing the incidence, mortality, or objective measures of severity or progression of chronic chest complications (chronic sickle lung and pulmonary hypertension) among men or women of any age and with one of four common sickle cell disease genotypes, i.e. Hb SS, Sβ0, SC, or Sβ+. These interventions would be compared to an alternative treatment with the same aim or to no treatment.

Data collection & analysis
No studies matching the selection criteria were found.

Main results
No studies matching the selection criteria were found.

Authors’ conclusions
There is a need for randomized controlled trials looking at the role of long-term transfusion therapy in pulmonary hypertension and chronic sickle lung disease. Due to the chronic nature of the conditions, such trials should aim to use a combination of objective and subjective measures to assess participants during an extended ‘steady state’ baseline, and after the intervention.
Abstract

Background
Thalassemia is an inherited blood disorder, caused by mutations in regulatory genes and transmitted as an autosomal recessive disorder, which results in a reduced rate of synthesis of one of the globin chains that make up haemoglobin. In β-thalassaemia major there is an underproduction of β-globin chains combined with excess of free α-globin chains. The excess free α-globin chains damage the red blood cell membranes, leading to their destruction and a phenomenon termed ineffective erythropoiesis. The conventional approach to treatment is based on the correction of haemoglobin status through regular blood transfusions and iron chelation therapy for iron overload. Although conventional treatment has the capacity to improve the quality of life of people with β-thalassaemia major, allogeneic hematopoietic stem cell transplantation is the only currently available procedure which has the potential to definitively cure the disease.

Objectives
To evaluate the effectiveness and safety of different types of allogeneic hematopoietic stem cell transplantation, in people with severe transfusion-dependant β-thalassaemia major, β-thalassaemia intermedia or β0/+- thalassaemia variants requiring chronic blood transfusion.

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

Date of the most recent search: 27 May 2011.

Selection criteria
Randomised controlled trials and quasi-randomised controlled trials comparing allogeneic hematopoietic stem cell transplantation with each other or with standard therapy (regular transfusion and chelation regimen).

Data collection & analysis
Two review authors independently screened studies and had planned to extract data and assess risk of bias using standard Cochrane Collaboration methodologies but no studies were identified for inclusion.

Main results
No relevant studies were retrieved after a comprehensive search of the literature.

Authors' conclusions
We were unable to identify any randomised controlled trials or quasi-randomised controlled trials on the effectiveness and safety of different types of allogeneic stem cell transplantation in people with severe transfusion-dependant β-thalassaemia major or β0/+- thalassaemia variants requiring chronic blood transfusion. The absence of high-level evidence for the effectiveness of these interventions emphasises the need for well-designed, adequately-powered, randomised controlled clinical trials.
Abstract

Background
Mucopolysaccharidosis II, also known as Hunter syndrome, is a rare, X-linked disease caused by a deficiency of the lysosomal enzyme iduronate-2-sulfatase, which catalyses a step in the catabolism of glycosaminoglycans. The glycosaminoglycans accumulate within tissues affecting multiple organs and physiologic systems. The clinical manifestations include neurologic involvement, severe airways obstruction, skeletal deformities and cardiomyopathy. The disease has a variable age of onset and variable rate of progression. In those with severe disease, death usually occurs in the second decade of life, whereas those patients with less severe disease may survive into adulthood. Enzyme replacement therapy with intravenous infusions of idursulfase has emerged as a new treatment for mucopolysaccharidosis type II.

Objectives
To evaluate the effectiveness and safety of enzyme replacement therapy with idursulfase compared to other interventions, placebo or no intervention, for treating mucopolysaccharidosis type II.

Search strategy
We searched the Cochrane Cystic Fibrosis and Genetic Disorders Group's Trials Register (date of last search 01 September 2011).

We also searched EMBASE, PubMed and the Literature Latino-Americana e do Caribe em Ciências da Saúde (LILACS) (date of last search October 2009).

Selection criteria
Randomised and quasi-randomised controlled trials of enzyme replacement therapy with idursulfase compared to no intervention, placebo or other options (e.g. behavioral strategies, transplantation).

Data collection & analysis
Two authors independently screened the trials identified, appraised quality of papers and extracted data.

Main results
One study (96 patients) met the inclusion criteria, although the primary outcome of this review - z score for height and weight, was not assessed in the study. Following 53 weeks of treatment, patients in the weekly idursulfase 0.5 mg/kg group demonstrated a significant improvement rate compared with placebo for the primary outcome: distance walked in six minutes on the basis of the sum of ranks of change from baseline, mean difference 37.00 (95% confidence interval 6.52 to 67.48). The every-other-week idursulfase 0.5 mg/kg group also showed an improvement, which was not significant compared with placebo, mean difference 23.00 (95% confidence interval -4.49 to 50.49). After 53 weeks, there was no statistical significance difference in per cent predicted forced vital capacity between the three groups and absolute forced vital capacity was significantly increased from baseline in the weekly dosing group compared to placebo, mean difference 0.16 (95% confidence interval 0.05 to 0.27). No difference was observed between the every-other-week idursulfase 0.5 mg/kg group and placebo.

In addition, liver and spleen volumes and urine glycosaminoglycan excretion were significantly reduced from baseline by both idursulfase dosing regimens. Idursulfase was generally well tolerated, but infusion reactions did occur. Idursulfase antibodies were detected in 31.7% of patients at the end of the study and they were related to a smaller reduction in urine glycosaminoglycan levels.

Authors' conclusions
The current evidence is limited. While the randomised clinical trial identified was considered to be of good quality, it failed to describe important outcomes. It has been demonstrated that enzyme replacement therapy with idursulfase is effective in relation to functional capacity (distance walked in six minutes and forced vital capacity), liver and spleen volumes and urine glycosaminoglycan excretion in patients with mucopolysaccharidosis type II compared with placebo. There is no available evidence in the included study and in the literature on outcomes such as improvement in growth, sleep apnoea, cardiac function, quality of life and mortality. More studies are needed to obtain more information on the long-term effectiveness and safety of enzyme replacement therapy.
## Asia-Pacific Region Workshops

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<td>Cochrane Review Completion and Review Update Workshop</td>
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<td>How to use Cochrane systematic reviews to answer questions about your patients</td>
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## Australasian Cochrane Centre

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## Brazilian Cochrane Centre

For more information see: [http://www.centrocochranedobrasil.org.br/](http://www.centrocochranedobrasil.org.br/)

## Canadian Cochrane Centre

For more information see: [http://ccnc.cochrane.org/workshops](http://ccnc.cochrane.org/workshops)

## Dutch Cochrane Centre

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## Iberoamerican Cochrane Centre

For more information see: [http://www.cochrane.es/](http://www.cochrane.es/)

## Nordic Cochrane Centre

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### UK Cochrane Centre

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### US Cochrane Centre

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<td>29 Mar – 01 Apr 2012</td>
<td>Baltimore</td>
<td>Research Methods Training in Complementary and Integrative Medicine</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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- 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):**

I would like to receive future mailings: Yes / No
Cochrane Cystic Fibrosis and Genetic Disorders Group

Summary sheet (Oct 2011)

September 1995  Registered with the Cochrane Collaboration as the Cystic Fibrosis Group
December 1997  Scope of group expanded to include other genetic diseases

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Group Website: http://www.liv.ac.uk/cfgd
Current funding: NHS R&D Programme, UK

Trial Registers

The register of randomised controlled trials (RCTs) for cystic fibrosis contains 1871 references to 1107 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 640 references to 334 trials, the coagulopathies register has 276 references to 191 trials, and there are also 146 references for phenylketonuria and 659 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 pleurodesis 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
Self-management education for cystic fibrosis
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
Cystic fibrosis protocols
Antibiotic treatment for *Stenotrophomonas maltophilia* in people with cystic fibrosis
Appetite stimulants for people with cystic fibrosis
Immunosuppressive drug therapy to prevent rejection following lung transplantation for cystic fibrosis
Inhaled antibiotics for pulmonary exacerbations in people with cystic fibrosis
Inhaled mannitol for cystic fibrosis
Interventions for promoting physical activity in people with cystic fibrosis
Nebuliser devices for drug delivery in cystic fibrosis
Pancreatic enzyme replacement therapy for people with cystic fibrosis
Recombinant growth hormone therapy for children and young adults with cystic fibrosis
Timing of hypertonic saline inhalation in cystic fibrosis
Vitamin E supplementation for 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
Regular long-term red blood cell transfusions for chronic chest complications in sickle cell disease
Splenectomy versus conservative management for acute sequestration crises in people with sickle cell disease
Stem cell transplantation for people with beta thalassaemia major
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
Angiotensin-converting enzyme (ACE) inhibitors for proteinuria in people with sickle cell disease
Deferasirox for iron chelation in people with transfusion-dependent thalassaemia
Interventions for treating leg ulcers in people with sickle cell disease
Zinc supplementation for thalassaemia and sickle cell disease
**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
Enzyme replacement therapy with idursulfase for mucopolysaccharidosis type II (Hunter syndrome)
Hematopoietic stem cell transplantation for Gaucher disease
Newborn screening for homocystinuria
Protein substitute for children and adults with phenylketonuria
Recombinant growth hormone therapy for X-linked hypophosphataemia 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 laronidase (Aldurazyme®) for treating mucopolysaccharidosis type I

**Orphan reviews**
Dietary advice for illness-related malnutrition in adults
Embolisation therapy for pulmonary arteriovenous malformations
Intravenous alpha-1 antitrypsin augmentation therapy for treating patients with alpha-1 antitrypsin deficiency and lung disease
Oral protein calorie supplementation for children with chronic disease

**Orphan protocols**
Pycnogenol® for the treatment of chronic disorders
Surgical interventions for treating pectus excavatum