December 2009
Issue 39

Editorial
Nikki Jahnke – Managing Editor

It was with some shock I realised recently that it was a full year since we last sent out our newsletter. We really have had a very busy year here at the CFGD Group.

As you will read on page 2, we received news of our funding for the next five years in January and were disappointed to find this had been cut. We successfully appealed and will remain at the current funding level for the next grant period.

We also took part in a Collaboration-wide ‘self audit’ led by the Editor-in-Chief. The results of this audit were published shortly before the Singapore Colloquium and discussed there. It was gratifying to see that we operate in line with most other review groups and indeed some aspects are better than several other groups. As a next step each group will be discussing their responses compared to ‘average’ responses with the Editor-in-Chief in order to standardise editorial practice across the Collaboration and improving relationships between Editorial Bases and authors.

There have been some personnel changes. In May Tracey gave birth to a daughter and has been on maternity leave since then. We have had a number of temporary staff to provide cover, but will be glad to welcome Tracey back in January. We would also like to welcome four new editors: Dr Alfonso Iorio (Coagulopathies); Dr John Walter (Inborn Errors of Metabolism); Dr Heather Elphick (CF); and Prof Felix Ratjen (CF). And finally, congratulations to our statistician Kerry who was awarded her PhD recently.

- Current Titles Registered -

• Regular long-term red blood cell transfusions for chronic chest complications in sickle cell disease
• Interventions for treating leg ulcers in people with sickle cell disease
• Inhaled mannitol for cystic fibrosis
• Vitamin K supplementation for cystic fibrosis
• Surgical interventions for treating pectus excavatum
• Newborn screening for homocystinuria

Output of the CFGD Group
83 reviews & 24 protocols will be published on Issue 1, 2010 of The Cochrane Library

What’s Inside:

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10-12
In January our funders, the NHS National Institute for Health Research, announced the levels of funding for the next five years. They decided to change the current ‘flat rate’ funding system in favour of a banded system with three levels of funding. Our review Group was allocated to the lowest band which would have had a severe impact in our future activities. After a lot of hard work by the Editorial Team we were able to successfully appeal the decision and were re-banded to the middle funding band. This means we will receive approximately our current level of funding until March 2015 allowing us to maintain our review production and continue to offer the same level of support to all our authors.

Part of the reason we were successful was that we put together a proposal to increase the number of reviews we publish on interventions for coagulopathies and for inborn errors of metabolism. We plan to publish a minimum of ten new reviews in each of these areas over the next five years. This is of course in addition to our commitment to continue review production in the other areas of our scope (haemoglobinopathies and cystic fibrosis).

As a first step, we have recruited two new editors who are key experts in their respective fields – Dr Alfonso Iorio is the new Coagulopathies editor and is currently working to update our two existing haemophilia reviews; and Dr John Walter is the new editor for inborn errors of metabolism and is currently working on a review of newborn screening for homocystinuria. In addition we have worked closely with them to identify priority titles for reviews in their respective areas and also to identify contacts who would be interested in undertaking one of these Cochrane reviews or who would be interested in peer reviewing these reviews. The revised list of priority titles is available from our website (www.cfgd.cochrane.org) or from the Editorial Base (nikkij@liv.ac.uk).

We have also worked on producing new titles for the other areas of our scope and plan to continue increasing our output for cystic fibrosis, sickle cell disease and thalassaemia. In order to maintain our efficient response times from the Editorial Base, we have recruited a further two editors for cystic fibrosis (Prof Felix Ratjen and Dr Heather Elphick).

Finally, some news that is hot off the press. As from January 2010 the Cochrane Database of Systematic Reviews (CDSR) and the ‘About The Cochrane Collaboration’ database will move to monthly online publication. This represents an important development for the CDSR and The Cochrane Library and the increased publication frequency will bring benefits to readers, authors, and editorial teams as new evidence will be published more rapidly. These changes will be implemented in phases.

**Phase 1:** The first issue of 2010 will be published on 20 January as already scheduled and will introduce some minor changes to the display of protocols and reviews to accommodate monthly publication.

**Phase 2:** The first module submission deadline for 2010 will be **21 January 2010**. Reviews and protocols submitted then will be published as Issue 2 in February 2010. Submission on a monthly basis will follow throughout 2010.

The DVD version of The Cochrane Library will remain as four issues per year. These will be labelled as: January [year]; April [year]; July [year]; and October [year]. The DVD will be a reflection of the online January, April, July, and October issues.

It looks like being an exciting time ahead and we will keep you informed of any other news as it happens.
Online Learning Resources

The UK Cochrane Centre have developed a set of Online Learning Resources for Undertaking a Systematic Review in conjunction with the University of Portsmouth. In the first instance, these are being made available to authors from any review group who have a registered title for a Cochrane review, have an active record in Archie and are located in the UK.

You can register for access via the UKCC homepage (www.cochrane.ac.uk). Click on the Online Learning Resources heading in the middle of the page which will then take you to pages with further information about the resources and how to register for a free user ID and password. If you have any questions, please contact Carly Toop at the UK Cochrane Centre (ctoop@cochrane.ac.uk).

The Cochrane Collaboration are exploring means to make the materials available to authors who are not based in the UK. The reasons for this staggered procedure relate to licensing of the underlying software and the provision of support to users outside the UK.

Cochrane Journal Club

The Cochrane Journal Club is a new Cochrane feature that was launched with issue 4 2009 as a free, online, monthly publication. Available at www.cochranejournalclub.com, Cochrane Journal Club introduces a recent Cochrane review, together with relevant background information and related resources, including a podcast explaining the key points of the review, discussion questions to help a reader to explore the review methods and findings in more detail, and even downloadable PowerPoint slides containing key figures and tables to facilitate the presentation of the Cochrane review at a Journal Club meeting. Aimed at trainees, researchers and clinicians alike, each Cochrane Journal Club focuses on a review of special interest, selected from the hundreds of new and updated reviews published in each issue of The Cochrane Library, highlighting practice-changing reviews, controversial conclusions, new methodology, evidence-based methods, and reviews from diverse clinical topics.

Cochrane Journal Club content is written by the review authors in collaboration with Mike Clarke (Podcast Editor and Director of the UK Cochrane Centre), and the Cochrane Editorial Unit.

Publicity Update on The Cochrane Library

Issue 4, 2009

One month after publication there have been over 830 pieces of recorded media coverage from Issue 4, 2009.

Almost half of the coverage is from the USA (49.9%), which is more than normal but likely due to a change in ‘tools’ where the publishers can now better identify the country a website is from. The remainder of the top 5 are India (12.9%), UK (9.8%), Australia (3.8%) and Canada (2.5%). The total number of countries identified with coverage of this issue is 44. The ten countries with the most coverage make up over 85% of all coverage.

10% of coverage has been in languages other than English, with a wide variety of other languages used: Spanish, Italian, French, Portuguese, Finnish, Vietnamese, German, Russian, Chinese, Arabic, Dutch, Romanian, Taiwanese, Japanese and Indonesian


Cochrane Cystic Fibrosis and Genetic Disorders Review Group
Singapore was the setting for the 17th annual Cochrane Colloquium in October. This was the first time that Asia had hosted the Colloquium and it was a great success. The Colloquium focused on the key challenges and opportunities both for the region and for the Cochrane Collaboration. The scientific programme, like Singapore itself, was designed to embrace the future while maintaining a healthy respect for the traditions of the past.

The themes of the four plenary sessions were chosen to reflect some of the major recommendations to emerge from the recently completed Strategic Review of The Cochrane Collaboration. The opening session focused on challenges and highlighted challenges faced specifically by policy makers and healthcare professionals in Asia and also on the challenges facing The Cochrane Collaboration which were described in the strategic review.

The first main plenary session discussed the role of The Cochrane Collaboration in capacity building on a global scale and highlighted initiatives from Thailand, South America, South Africa and the ViTaMIN (Virtual Training and Mentoring International Network). As a final part of this session the Editor-in-Chief, David Tovey, gave a presentation on proposals for working more closely with the WHO.

The second main plenary session focused on issues surrounding the increasing complexity of Cochrane reviews such as reviews of traditional Chinese medicine, the incorporation of varying study designs in reviews and the problems applying review conclusions to clinical practice in a range of locations and settings.

The closing session gave us a chance to look to the future and how we can embrace technology to communicate our reviews better to the world outside of Cochrane. Did you know that The Cochrane Collaboration are now on Facebook and Twitter?!

Video slidecasts of all four plenary sessions are available via the Cochrane multimedia portal at http://www.cochrane.org/multimedia/index.html.

There were also a wide range of workshops during the four days of the Colloquium which covered practical and technical aspects of systematic reviewing as well as discussions of issues that face authors and the Collaboration in general. There were over 130 posters presented and these can be viewed online at http://www.cochrane.org/colloquium/2009/virtual_posters/.

An interesting article……

Background
Sickle cell disease (SCD) is an inherited autosomal recessive blood condition and is one of the most prevalent genetic blood diseases worldwide. Acute chest syndrome (ACS) is a frequent complication of sickle cell disease, as well as a major cause of morbidity and the greatest single cause of mortality in children with SCD. Standard treatment may include intravenous hydration, oxygen as treatment for hypoxia, antibiotics to treat the infectious cause and blood transfusions may be given.

Objectives
To assess the effectiveness of blood transfusions, simple and exchange, for treating ACS by comparing improvement in symptoms and clinical outcomes against standard care.

Search strategy
We searched The Group’s Haemoglobinopathies Trials Register, which comprises references identified from comprehensive electronic database searches and handsearching of relevant journals and abstract books of conference proceedings.
Most recent search: 27 March 2009.

Selection criteria
Randomised controlled trials and quasi-randomised controlled trials comparing either simple or exchange transfusion versus standard care (no transfusion) in people with sickle cell disease suffering from acute chest syndrome.

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
There is currently no reliable evidence to support or refute the effectiveness of blood transfusions as treatment options for acute chest syndrome in people with sickle cell disease. Well-designed, adequately-powered randomised controlled trials are now required to assess the benefits and risks of this form of treatment.
# 2010 Timetable for Cochrane Workshops

**Australasian Cochrane Centre**  

**Brazilian Cochrane Centre**  
For more information see: [http://www.centrocochranedobrasil.org/](http://www.centrocochranedobrasil.org/)

**Canadian Cochrane Centre**  

**Dutch Cochrane Centre**  
For more information see: [http://www.cochrane.nl/index.html](http://www.cochrane.nl/index.html)

**German Cochrane Centre**

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<tr>
<th>Date</th>
<th>Location</th>
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<tr>
<td>18 – 20 March</td>
<td>Freiburg</td>
<td>22nd Workshop on Systematic Reviews in Medicine</td>
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<tr>
<td>19 – 20 March</td>
<td>Freiburg</td>
<td>5th workshop Grading of evidence and recommendations - GRADE</td>
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**Iberoamerican Cochrane Centre**  
For more information see: [http://www.cochrane.es/Agenda](http://www.cochrane.es/Agenda)

**Nordic Cochrane Centre**

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<tr>
<td>20 April</td>
<td>Copenhagen</td>
<td>Developing a Protocol for a Review</td>
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**South African Cochrane Centre**  
For more information see: [http://www.mrc.ac.za/cochrane/project.htm](http://www.mrc.ac.za/cochrane/project.htm)

**US Cochrane Centre**  
For more information see: [http://apps1.jhsph.edu/cochrane/](http://apps1.jhsph.edu/cochrane/)

**UK Cochrane Centre**

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<td>Oxford</td>
<td>Developing a Protocol for a Review</td>
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<td>21 January</td>
<td>Oxford</td>
<td>Introduction to analysis</td>
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<td>10 March</td>
<td>Bath</td>
<td>Developing a Protocol for a Review</td>
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<td>11 March</td>
<td>Bath</td>
<td>Introduction to analysis</td>
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<td>18 – 21 May</td>
<td>Nottingham</td>
<td>The Nottingham Systematic Review Course</td>
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<tr>
<td>08 June</td>
<td>Glasgow</td>
<td>Developing a Protocol for a Review</td>
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<tr>
<td>09 June</td>
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<td>Introduction to Analysis</td>
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**Asia-Pacific Region Workshops**

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<tr>
<td>11 – 13 January</td>
<td>Vellore</td>
<td>Winter Symposium and 3rd South Asian Regional Symposium on Evidence-Informed Healthcare</td>
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<tr>
<td>08 February</td>
<td>Vellore</td>
<td>Introduction to Evidence-Informed Healthcare</td>
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**Cochrane Cystic Fibrosis and Genetic Disorders Review Group**
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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Johns Hopkins Bloomberg School of Public Health
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Fax: +1 410-502-4621
E-mail: uscc@cochrane.us
http://www.cochrane.us
- Contact Details -

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) :

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

The register of randomised controlled trials (RCTs) for cystic fibrosis contains 1766 references to 1055 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 582 references to 318 trials, the coagulopathies register has 276 references to 191 trials, and there are also 140 references for phenylketonuria and 657 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

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
Antimicrobial susceptibility testing for acute exacerbations in chronic infection with *Pseudomonas aeruginosa* in people with cystic fibrosis
Bisphosphonates for osteoporosis in people with cystic fibrosis
Chemical pleurodesis versus surgical intervention for persistent and recurrent pneumothoraces in cystic fibrosis

Cystic fibrosis -related arthritis

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

Cystic fibrosis treatment

Elective versus symptomatic intravenous antibiotic therapy for cystic fibrosis
Enteral tube feeding for cystic fibrosis

Hospital 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
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
PEP physiotherapy for airway clearance in cystic fibrosis
Physical training for cystic fibrosis
Prophylactic anti-staphylococcal antibiotics for cystic fibrosis
Psychological interventions for people with cystic fibrosis and their families
Single versus combination intravenous antibiotic therapy for people with cystic fibrosis

Sodium channel blockers for cystic fibrosis
Topical cystic fibrosis transmembrane conductance regulator gene replacement for cystic fibrosis-related lung disease
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
Cystic fibrosis protocols
Active cycle of breathing technique for cystic fibrosis
Antioxidant micronutrients for inflammation and oxidation in cystic fibrosis lung disease
Appetite stimulants for people with cystic fibrosis
Inhaled antibiotics for pulmonary exacerbations in people with cystic fibrosis
Nebuliser devices for drug delivery in cystic fibrosis
Neuraminidase inhibitors for the treatment of influenza infection in people with cystic fibrosis
Non-antibiotic therapies for pulmonary infection in cystic fibrosis
Palivizumab for prophylaxis against respiratory syncytial virus infection in children with cystic fibrosis
Pancreatic enzyme replacement therapy for people with cystic fibrosis
Percutaneous long lines for administering intravenous antibiotics in people with cystic fibrosis
Self-management education for cystic fibrosis
Singing for children and adults with cystic fibrosis
Timing of dornase alfa inhalation for cystic fibrosis
Topical nasal steroids for treating nasal polyposis in people with 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
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
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 sickle cell disease
Deferasirox for iron chelation in people with transfusion-dependent thalassaemia
Gene therapy for 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
Hematopoietic stem cell transplantation for Gaucher disease
Protein substitute for children and adults with phenylketonuria
Recombinant growth hormone therapy for X-linked hypophosphatemia in children
Tyrosine supplementation in phenylketonuria

Inborn errors of metabolism protocols
Enzyme replacement therapy for Fabry disease
Enzyme replacement therapy with idursulfase for mucopolysaccharidosis type II (Hunter syndrome)
Intravenous alpha-1 antitrypsin augmentation therapy for treating patients with alpha-1 antitrypsin deficiency and lung disease
Sapropterin dihydrochloride for phenylketonuria
Statins for familial hypercholesterolemia in children

Orphan reviews
Dietary advice for illness-related malnutrition in adults
Oral protein calorie supplementation for children with chronic disease

Orphan protocols
Embolisation therapy for pulmonary arteriovenous malformations
Proanthocyanidin supplements for the treatment of chronic disorders