



## Affiliates Newsletter – May 2011

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### MESSAGE FROM THE CHAIR

Dear colleague,

We are pleased to bring you our latest Newsletter, from which you will see there is still plenty going on – and even more to learn.

The James Lind Alliance has now formally existed for four years, but this followed two years preliminary work to ensure that the idea was worth pursuing. We are very grateful for the funding provided by NIHR and MRC, and it has always been understood and agreed that this would come to an end in March 2013. This is entirely right given the economic climate and, more importantly, the acid test, to show that the concept is good enough to fly by itself.

I am delighted to report that negotiations are in train for the work of JLA to be embraced within a Department of Health organisation after March 2013. In the meantime, however, we are working at full tilt to help and encourage our Priority Setting Partnerships and to develop and learn from our experience, so that we can leave a meaningful legacy.

Please continue to maintain your enthusiastic dialogue with us and spread the word of what we do.

If there is anything else you would like to see us report in our Newsletter, please get in touch with Katherine, whose contact details are on page 10.

Thanks, as always, for your support,

Lester Firkins, Chair, James Lind Alliance

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## NEWS

### JLA Affiliates programme continues to grow

Since the JLA re-launched its Affiliates programme in September last year, membership has increased by almost 70 per cent. Our members are wide-ranging, from individual patients and clinicians who feel passionate about their involvement in research priority setting, to organisations as diverse as the British Dental Association, the Pelvic Pain Support Network, Tourettes Action, the Academy for Eating Disorders, Parkinson's UK and Cancer Voices NSW in Australia. Our Affiliates are an integral part of our strategy to promote the important role patients, carers and clinicians can play in deciding what gets researched.

We hope that you will also benefit from being part of a wide network of like-minded organisations and individuals. One of our most active Affiliates, Kim Thomas, Associate Professor (non-clinical) and Deputy Director of the Centre of Evidence Based Dermatology, recently said: "Working with the JLA has been a great experience. It's always a pleasure to work with a group of professional, enthusiastic and dedicated individuals; and that is certainly what we've encountered in our work with the JLA team. We've learnt a lot along the way, but hope we've also played a small part in



Kim Thomas

contributing to the development and overall success of the JLA. We're now into our second PSP and are looking forward to applying some of the lessons from our first."



As Affiliates, if you would like to promote your link with the JLA on your website, please let us know, and we can send you a copy of our logo to use. We would like to ask all our existing Affiliates to encourage their colleagues and partners to find out more about the JLA and our methods for research priority setting by becoming Affiliates: feel free to forward this newsletter on to them or refer them to [www.lindalliance.org/Affiliates-Programme.asp](http://www.lindalliance.org/Affiliates-Programme.asp).

### New website: Involving London

Involving London is a new website designed to enable patients and the public to find out how they can get involved in health and social care research and to get up-to-date information on current research opportunities. The website aims to bring patients and the public together, to work with researchers who are looking for people to get involved in research studies across the capital. Involving London was set up by Patient Public Involvement Leads and Managers from various NHS trusts, research networks/centres and support services. Each organisation will use the website to promote research opportunities, in specific disease groups, research groups or local areas. Go to [www.involvinglondon.co.uk](http://www.involvinglondon.co.uk) to find out more.



## JLA PRIORITY SETTING PARTNERSHIPS UPDATE

JLA Priority Setting Partnerships (PSPs) are comprised of patients, carers and clinicians working together to identify treatment uncertainties and to prioritise these for research. Individuals, groups or consortia interested in forming a JLA Priority Setting Partnership should visit [www.JLAguidebook.org](http://www.JLAguidebook.org) or contact Patricia Atkinson ([patkinson@lindalliance.org](mailto:patkinson@lindalliance.org)).

### Type 1 Diabetes

The final workshop for the Type 1 Diabetes PSP took place in London on 24th May. Sixteen participants were eligible to vote on their priorities for research, as they were either people with type 1 diabetes, people caring for those with the condition, or clinicians treating it. There were a further three observers present. An intense but enjoyable day culminated in the agreement of a shared top 10 set of priorities for research, plus an overarching aspiration for research. More details will be shared in the next newsletter. For information contact Sally Crowe on [sally@crowe-associates.co.uk](mailto:sally@crowe-associates.co.uk).

### Life After Stroke in Scotland

Dr Alex Pollock, Research Fellow at the Nursing, Midwifery and Allied Health Professionals (NMAHP) Research Unit, Glasgow Caledonian University, reports:



“The life after stroke in Scotland PSP has gathered over 500 treatment uncertainties, and the Steering Group has now moved on to the process of checking that these are true uncertainties, merging duplicate questions and rewording the questions in a PICO format. We are also considering how to reduce the number of treatment uncertainties down to a manageable number to take forward for interim prioritisation. As approximately one third of the submitted uncertainties are not intervention questions (many being prevalence and prognosis questions), it has been decided that these non-intervention questions will be excluded from the current prioritisation process. We will then carry out an interim prioritisation process in which the remaining ‘true’ intervention uncertainties will be sent out to patients, carers and health professionals who will be asked to identify and order their personal top 10. We anticipate that identifying a personal top 10 from a list of approximately 300 uncertainties is going to be a challenge for all participants. However, those participants with stroke-related difficulties relating to functions such as communication, vision, cognition, executive function (which covers the processes of planning and decision making) may find this task particularly difficult. We hope that we will be able to find ways which will make the process as easy as possible – for example, categorising the uncertainties in key ‘problems’ after stroke. As we did for the first phase of the project, we will also facilitate involvement by visiting stroke clubs and groups. The aim is to start this interim prioritisation process in August 2011.”

To find out more, contact Alex at [Alex.Pollock@gcu.ac.uk](mailto:Alex.Pollock@gcu.ac.uk) or go to [www.askdoris.org/D\\_JLA.asp](http://www.askdoris.org/D_JLA.asp).

### Head and Neck Cancer

This PSP led by ENT UK and Head and Neck 5000 is now at the stage of gathering uncertainties. Announcements have been sent to a wide range of interested groups and individuals. A closing date for receipt of 10th June has been set and so, at the moment, all efforts are being applied to encourage a high number of submissions. For more information, please contact Jo White at [Jo@entuk.org](mailto:Jo@entuk.org), or visit the JLA website: [www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp](http://www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp).



## Ear, Nose and Throat – Aspects of Balance



The final priority setting workshop is scheduled for 31<sup>st</sup> May and will be fully reported in the next newsletter. “We are at that interesting moment in time when you can never be sure how many people will turn up to vote – and whether we will naturally have an equal number of clinicians and patients,” says Lester Firkins, who chairs the PSP. “As always, there is a great deal of lobbying and cajoling going on to get the fullest possible attendance.” If you would like any further information on this PSP, please contact Jo White [jo@entuk.org](mailto:jo@entuk.org).

## Pressure Ulcers

An awareness meeting was held in March which was well attended by people living with and at risk of pressure ulcers, and clinicians and researchers interested in their treatment. The morning discussions yielded many potential treatment uncertainties for pressure ulcers, from a range of perspectives. The afternoon session focussed on how the partnership would work and what partners could contribute to the process. A workshop report is being written, and a steering group being assembled. A full time research fellow will be appointed in May this year, to support this partnership to its conclusion. To keep up to date with progress visit the PSP’s website [www.ilapressureulcerpartnership.co.uk](http://www.ilapressureulcerpartnership.co.uk). For further information on the next stages please contact Dr. Mary Madden ([mary.madden@york.ac.uk](mailto:mary.madden@york.ac.uk)) or Sally Crowe ([sally@crowe-associates.co.uk](mailto:sally@crowe-associates.co.uk)).

## Lyme Disease

On 18<sup>th</sup> May the JLA Lyme Disease PSP held its first meeting in London. Lyme Disease Association (LDA) chair, Stella Huyshe-Shires, described the events that had led to the formation of this PSP. She discussed the lack of clinician experience and the fact that guidelines for Lyme disease rest on a very thin evidence base. The UK situation on diagnosis and treatment was described by Caroline Rayment, a Yorkshire GP who recently contracted Lyme disease. She described her experience as a patient, which was familiar to all the patients present. Lester Firkins, chair of this PSP, described the JLA process and Matthew Hall, an information specialist, explained the concept of treatment uncertainties. “Everyone found the day beneficial,” said Stella. “Although people had read about this, there really is nothing quite like a face-to-face meeting with dedicated time set aside to concentrate on the subject.” There are a couple of meetings in Scotland to come and then this PSP will be forming a steering group. Finding interested clinicians for the partnership is looking tricky given the lack of interest so far, but this has been the initial situation for other PSPs and is not an insurmountable challenge. For further information on this PSP, please contact Stella Huyshe-Shires at [Stella.Huyshe@LymeDiseaseAction.org.uk](mailto:Stella.Huyshe@LymeDiseaseAction.org.uk).



## Pre-term Birth

The aim of the Pre-term Birth PSP is to identify the unanswered questions about the effects of care and treatment for pre-term babies, as raised by service users and clinicians. Peri-natal and neonatal interventions will be included, although prevention will be excluded. Once the questions are identified, the most important will be prioritised by agreement between clinicians and service users. An initial partnership meeting will be held on 14th July at the Institute of Education, University of London. The workshop will be hosted by the



Social Science Research Unit (SSRU), which is part of the Institute of Education. Clinicians, service users and carers who are involved in preterm birth and care are all welcome to attend. For more information and to book your place, please contact Seilin Uhm ([s.uhm@ioe.ac.uk](mailto:s.uhm@ioe.ac.uk), 020 7612 6532) or visit the Pre-term Birth PSP website: <http://epi.ioe.ac.uk/pretermbirth>.

## Eczema

This PSP has had its first Steering Group meeting, where people living with eczema, charity representatives, clinicians and researchers agreed the key tasks and milestones of the process and a protocol for developing the PSP. Steering Group members have helped to shape the eczema treatment uncertainty survey, which is currently being piloted. With the help of the National Eczema Society, the Nottingham Eczema Support Group at the Centre of Evidence Based Dermatology (CEBD), University of Nottingham, will manage and support this PSP as part of their wider NIHR Programme Grant – Setting Priorities and Reducing Uncertainties for People with Skin Disease (SPRUSD). For more information, contact Tessa Clarke, Senior Clinical Trials Development Manager: [Tessa.Clarke@nottingham.ac.uk](mailto:Tessa.Clarke@nottingham.ac.uk).

See page 6 for an interview with consultant dermatologist on treatment uncertainty in eczema.

## Cleft Lip and Palate

The Cleft Lip and Palate PSP now has an established Steering Group, including representatives from the Cleft Lip and Palate Association (CLAPA), the British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS), Birmingham Children’s Hospital and the University of Bristol. Professor Nicky Kilpatrick, Paediatric Dentist at the University of Bristol, said of the initiative: “The Cleft PSP is not only important for establishing the research priorities for us in this country but also a great opportunity to engage with patients and their families in a really meaningful manner, which will hopefully pave the way for a closer working relationship in the future”. An initial awareness meeting for interested patients, families and clinicians is being held in Birmingham on Saturday 11th June, 10:30am-3:30pm. This is an opportunity to hear more about the PSP and the JLA, and to find out how to get involved in the process of identifying and prioritising uncertainties about cleft lip and palate, including diagnosis, aetiology and prognosis. For more information please contact Katherine Cowan: [katherine@katherinecowan.net](mailto:katherine@katherinecowan.net).

## Priority setting in the South West

The JLA recently met up with the Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC), to share experiences and ideas for patient and clinician involvement in research priority setting. Here, Andy Gibson, Research Fellow at PenCLAHRC’s Patient and Public Involvement Team, explains more about the exciting work happening in the South West.

PenCLAHRC is a collaboration of Universities and NHS organisations in the South West of England which aims to deliver high-quality health research that improves medical practice. An important part of this work is ensuring that the research we carry out addresses the needs and priorities of clinicians, patients and carers and results in beneficial new treatments and services. In order to make sure that this happens we are developing the involvement of clinicians, service users and carers throughout the research process.



Andy Gibson



People can get involved in PenCLAHRC research in a number of ways, for example, in developing research questions, helping to prioritise research projects, advising on existing projects or helping to ensure that the findings from research are put into practice.

PenCLAHRC takes questions raised by lay people, along with those from clinicians and academics and decides which to develop into research projects. To do this we consider factors such as:

- How common is the health problem?
- What is the potential for health improvement?
- How practical would it be to try to answer the research question?
- Is the local area an appropriate place to address the question?

“Patients and carers are represented on the group that makes these decisions. For projects that are taken forward, patients and carers stay involved in planning the work and making sure their perspective is taken into account.”

*If you'd like to get involved or find out more please telephone Andy Gibson on 01392 262913 or e-mail him on [andy.gibson@pms.ac.uk](mailto:andy.gibson@pms.ac.uk) or visit: <http://clahrc-peninsula.nihr.ac.uk>*

**Peninsula CLAHRC**  
the NIHR CLAHRC of the South West Peninsula

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### **A clinician's perspective: interview with Jonathan Batchelor, Consultant Dermatologist**

The work of the JLA aims to impact not only patients, but also the clinicians who treat them. Despite the challenges brought by busy schedules and heavy workloads, clinician involvement is a key feature for a successful Priority Setting Partnership (PSP). Jonathan Batchelor, a Consultant Dermatologist at Queen's Medical Centre in Nottingham, has been involved in two PSPs- vitiligo and eczema- funded by a National Institute for Health Research Programme Grant. He talks to Katherine Cowan about his work and the importance of working with patients and carers to address treatment uncertainty.



*KC: Can you tell me about your current role?*

JB: I'm a Consultant Dermatologist and I also work one day a week at the Centre of Evidence Based Dermatology at the University of Nottingham, so I have a mixed clinical and research role.

*So in terms of your career, how did you get to where you are now?*

While I studying was at Nottingham Medical School, I became really interested in dermatology, partly because of the enthusiasm of consultants and registrar colleagues in the department, and because patient involvement in dermatology research was being championed. I graduated in the year 2000, spent a year as a junior doctor in Nottingham and Great Yarmouth, then spent two years in Japan, doing language study and research. I came back to the UK to continue my medical training in London



and Brighton, then moved to Cambridge as a dermatology registrar. After four years, I moved to Nottingham last year as a consultant.

*What do you enjoy most about your job?*

In terms of the speciality of dermatology, I gravitated towards it because of the variety: there are two or three thousand skin conditions- no one knows the exact number- some of which are very common and some which are very rare. I enjoy the fact that I work with patients of all ages: children and their parents and carers, and adults. Although we treat many patients with creams and tablets, I am also able to do a surgery list once a week as well, which adds a more practical dimension to my job. I also enjoy that fact that my colleagues are very passionate about the speciality, and very committed to research. Dermatology is an specialty where there's a huge amount of uncertainty regarding the best treatments, and more high-quality research is really needed, particularly well-designed clinical trials.

*You're currently involved in the JLA Eczema PSP. What are the main issues you're seeing around eczema in your clinical work?*

Eczema is a very itchy skin condition which tends to affect the arms, legs, elbows and knees. It can create small blisters on the skin, filled with fluid, and you can get breaks in the skin, allowing bacteria in, creating infections on top of the eczema. It is interesting to contrast eczema to psoriasis, a skin condition in which there has been huge progress in treatment options in the past decade. These treatments have revolutionised the care of psoriasis patients, who can return much more easily to their daily lives. In contrast, we don't yet have such 'golden bullet' treatments for eczema – that really is the 'holy grail' of eczema research. Yet eczema is extremely common and it represents a huge burden on people who have it, particularly young children. The impact of eczema is very large, not only because of the physical suffering it causes, such as itching and loss of sleep, but also the psychological suffering and impact on self-esteem. These in turn put huge pressure on parents and carers of children with eczema. Where patients are very self-conscious about the appearance of their skin, it can limit their activities and restrict their lives. It's a very sad thing and something which would be great to address, and yet there is still so much uncertainty about the best way to treat patients,



especially children. That's why it's so important that research is driven forward, and that we look not just at what doctors and researchers think is important, but that we also look at what's important to children and adults with eczema and their carers.

*Clearly treatment uncertainty is a major issue for eczema, and a key theme for the JLA Eczema PSP. What has your involvement with the PSP been so far?*

The PSP is in its early stages, but we've formed a Steering Group, and I sit on that with a mix of patient representatives, clinicians involved in eczema care and researchers. We're starting to think about how we will execute the priority setting process. Previously I was involved in the Vitiligo PSP. It was already up and running

when I joined the Steering Group, and I got involved in sorting through the uncertainties which were gathered through the online survey, checking them and grouping them into categories and into indicative uncertainties. I also attended the final prioritisation workshop. I really enjoyed working alongside patients and other healthcare professionals. It was a tiring day, but very interesting and I felt that everyone had a chance to express their views on the ranking of the top 10 uncertainties; it was a very fair and democratic process.

*As a clinician, what did you get out of being involved in an exercise where patients, carers and clinicians were contributing equally?*

I think what it showed me was just how actively involved some patients want to be in the research process, how knowledgeable they are, and how important it is for their voice to be heard as part of the process. I was aware that from the clinicians' perspective, we had our own ideas of what we thought might be important, and what was interesting was that while there was some overlap with what patients thought was important, there were also some significant differences. Without having a process like the JLA one, I certainly wouldn't have been aware of those views. It really opened my eyes and showed me the importance of not assuming that doctors know the most important areas that need to be researched.

*What are your main aspirations for the Eczema PSP?*

It's important because there is still so much uncertainty despite it being a common condition. It's very easy as a dermatologist working with patients with eczema to lose sight of what really matters to those patients. Going through a process to find out what answers they want to know is vital. It's very difficult in the clinical setting to know what patients as a whole group want to know. We need to know where the most important uncertainties in the treatment of eczema are so we can drive forward effective and high quality research in the future. It's a chance to give direction to dermatology researchers across the world.

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## IN PRINT

Eleftheriadou, V., Whitton, M., Gawkrödger, D., Batchelor, J., Corne, J., Lamb, B., Ersser, S., Ravenscroft, J., Thomas, K. and on behalf of the vitiligo priority setting partnership (2011), **Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership.** *British Journal of Dermatology*, 164: 530–536. doi: 10.1111/j.1365-2133.2010.10160.x

This article describes the work of the Vitiligo Priority Setting Partnership and describes how vitiligo treatment uncertainties were gathered from patients and clinicians, and then prioritised in a transparent process, using the JLA methodology. It concludes that the top 10 research areas for the treatment of vitiligo provide guidance for researchers and funding bodies, to ensure that future research answers questions that are important both to clinicians and to patients. The article can be read in full at <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2133.2010.10160.x/full>.



The following letter from Lester Firkins was recently published in **New Scientist** magazine (issue 2801):



*Dan Hind's article about the democratisation of research funding allocation, and the ensuing correspondence, raises provocative questions about who chooses what research gets done (11 December 2010, p 26). However, it fails to take into account the strides already made in this direction.*

*Since losing my son to vCJD in 2001, I have been involved with, and now chair, the James Lind Alliance. Supported by UK public funds, the JLA enables clinicians, patients and carers to agree which areas of research matter most to them. The premise is that researchers and the drug industry have, for too long, dominated decisions about funding, and that those at the sharp end, the ill and those who care for them, must be involved in deciding key research.*

*Iain Chalmers, a driving force behind the JLA and the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), cites several examples of the benefits of lay involvement in research. Though he concedes the need to build a formal evidence base for its effectiveness, he adds that many people "may feel that greater lay involvement in a pattern of research decision-making which has been dominated by professional researchers is justified on the basis of existing informal experience, common sense and justice".*

*Dan Hind may not have used the phrase, but common sense and justice can take us a long way.*

Chafe, R. (2011), **The rise of people power**. *Nature*, Vol. 471 (24 April 2011), pp. 2-3.

This article explains how calls in Canada for trials of a contentious treatment for multiple sclerosis illustrate how social media can affect research priorities. It urges scientists and research funders to "avoid adopting an 'us versus them' mentality", noting that "many researchers have been frustrated by the lack of impact that science often has on public debates, but new models for engagement are emerging." It cites the JLA as one example of this.



## ON THE WEB

Stay up to date with our work at [www.lindalliance.org](http://www.lindalliance.org). The site is regularly updated and has an interactive noticeboard, to which you can add information on your organisation's events or other news relating to patient and clinician involvement in priority setting in research.



For practical guidance on establishing a PSP and working with patients and clinicians to identify and prioritise treatment uncertainties for research, please visit our online Guidebook: [www.JLAguidebook.org](http://www.JLAguidebook.org). The Guidebook features examples of existing PSPs, including documents and templates to download and use.



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## CURRENT AFFILIATES

The JLA Affiliates programme is for organisations and individuals who identify strongly with the objectives of the JLA, and want to express support for, be involved in or simply be kept informed of the JLA's activities. It's quick, easy and free to become a JLA Affiliate. You'll receive a bi-monthly newsletter and will become part of an ever-expanding network of decision-makers, influencers and pioneers committed to involving patients and clinicians in research priority setting. If you're not already an Affiliate, please go to [www.lindalliance.org/Affiliates-Programme.asp](http://www.lindalliance.org/Affiliates-Programme.asp) to sign up.

The JLA currently has 357 Affiliates, most of whom are listed on our website. One of our newest Affiliates is Misophonia UK, which is seeking to foster greater awareness of sound sensitivity amongst doctors and the general public. Guy Fitzmaurice, Director, explains: "Misophonia is a little-known but surprisingly common neuro-otological disorder that affects children in particular. Sufferers become hyper-aware and obsessed with sounds, feeling immediate and intense rage at, for example, others' eating and breathing sounds. We have registered a treatment uncertainty with UK DUETs, as misophonia has so far proved impervious to treatment. For instance, it does not generally respond to therapies that reduce or eliminate phobias. We try to encourage the improvement of sufferer's and their families' coping skills." For more information, go to [www.misophonia-uk.org](http://www.misophonia-uk.org).



Guy Fitzmaurice

**misophonia uk**  
taking sound sensitivity seriously™

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## WANT TO FIND OUT MORE?

If you are new to the JLA or simply want to find out more about patient and clinician involvement in research priority setting, please visit [www.lindalliance.org](http://www.lindalliance.org). In the Publications section you will find a downloadable bibliography, along with an archive of useful JLA publications.

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## KEEP IN TOUCH

We hope you have enjoyed the latest JLA Affiliates Newsletter. Please contact us with any news, feedback, updates or information you would like to see featured in the next edition in July 2011.

Katherine Cowan  
James Lind Alliance  
Summertown Pavilion  
Middle Way  
Oxford OX2 7LG

[katherine@katherinecowan.net](mailto:katherine@katherinecowan.net)  
[www.lindalliance.org](http://www.lindalliance.org)

