



Affiliates Newsletter –January 2012

MESSAGE FROM THE CHAIR

Dear colleague,

Welcome to the first newsletter of 2012 – and a happy New Year to all our readers.

2012 is a watershed for us at the JLA: it will be the last full year of the JLA's first phase of development.

Over the past 18 months we have been planning for an important transition. During the 6 years of NIHR and MRC funding support received through the James Lind Initiative, we needed to show that the JLA concept held water and appeals to patients, carers and clinicians, and at least some elements of the medical research community. Due in no small part to the enthusiasm and overt support of you, our Affiliates, we have reached this stage, and, from March 2013, the JLA name and process will be taken over by our colleagues at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) in Southampton.

We are working on the detail for this migration now – but you can be certain that the key elements of what JLA offers will be maintained, and actually enhanced for broader application. Indeed, JLA's new home could not be more logical, given that so many of the top ten uncertainties generated by JLA Priority Setting Partnerships end up with the Health Technology Assessment (HTA) programme (which falls within NETSCC),

Over coming months we will keep you posted on developments. But rest assured that, in the meantime, our efforts with individual PSPs and our work to promote the importance of patient, carer and clinician involvement in research priority setting will continue unabated.

With every good wish for 2012 and beyond.

Thanks as ever for your support,

Lester Firkins, Chair, James Lind Alliance



NEWS

Lester Firkins OBE

Too modest to tell you in his introduction to this newsletter, Lester Firkins, chair of the JLA Strategy and Development Group, was recognised for services to medical research in the New Year's Honours List. Lester's journey into medical research began tragically in 2001 when his son Ellis died of vCJD. Working at the time as a banker, he had no knowledge of medical research, and, as he says "As a bereaved parent I had a choice: give up, or do something that might help others." Lester went on to chair the Human BSE Foundation, co-chair the Prion-1 vCJD treatment trial and a "new therapies scrutiny group," chair monthly meetings of the two principal CJD research groups in the UK, to ensure they collaborated, and joined the advisory group for a systematic review of prion disease treatments.

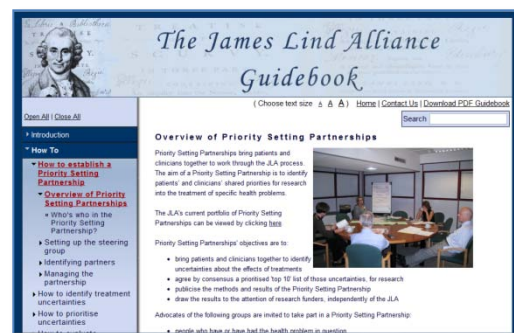
He says his work with the JLA brings these strands together, allowing him to dedicate himself to an organisation set up to ensure treatment research reflects the wishes of patients, carers and health professionals. Lester and his wife Wendy also worked closely with the Y Touring theatre company as they turned Ellis' story into a play, Starfish, to help young people understand clinical trials (www.theatreofdebate.com/Resources/Resources/Starfish/Download.html). Lester says he hopes the Honour he has received will help to promote mainstream acceptance of the principles about research which he holds dear: "Clinical research must always heed the wishes of those who are ill and those who care for them – that this is still not normal practice is arrogant and irresponsible on the part of those who fund or conduct research 'in our name.' Patients' interests must never play second fiddle to academic competition."



Lester Firkins

The JLA Guidebook – latest edition now online

The JLA Guidebook (www.JLAguidebook.org) is the JLA's online resource for setting research priorities with patients, carers and clinicians. Launched in May 2010, the guidebook was co-written by Professor Sandy Oliver and Katherine Cowan. It aims to provide practical, evidence-based guidance on the JLA's priority setting process, from setting up a Steering Group and holding an initial awareness meeting, to bringing patients, carers and clinicians together to prioritise their uncertainties for research. As well as providing straightforward advice, the Guidebook includes a wide range of practical examples of the work of the JLA's existing Priority Setting Partnerships. New partnerships can use these to get a feel for the work involved in the priority setting process, or to inform the development of their own materials. The updated version includes: a wider range of examples of uncertainty surveys; templates to assist with the preparation of data for the UK Database of Uncertainties about the Effects of Treatments (UK DUETs); new publications on the schizophrenia, urinary incontinence and prostate cancer partnerships; and an updated Protocol document for all new partnerships, as well as much more. Go to www.JLAguidebook.org, where a PDF version of the Guidebook can also be downloaded and printed out free of charge.



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 or contact Patricia Atkinson (patkinson@lindalliance.org).

Head and Neck Cancer

This PSP is nearing the end of the “harvesting of uncertainties ” stage and work will soon begin on sorting them out, in readiness for initial stage voting. For further information about this PSP, go to www.lindalliance.org/HeadandNeckCancerJLAPrioritySettingPartnership.asp. Or contact Jo White at Jo@entuk.org.

Pressure Ulcers

Richard Morley, Project Support Officer for the PSP at the Department of Health Sciences, University of York, reports:
"The JLA Pressure Ulcer Partnership is gearing up to begin its work in gathering uncertainties in the prevention and treatment of pressure ulcers (bed sores). At its November meeting, the Steering Group agreed its methods and timelines for gathering, analysing, prioritising and integrating uncertainties. The partnership has now gained ethics approval from the NHS to distribute its questionnaire among patients and carers in three areas of the country: York, Leeds and Middlesbrough. The partnership is also shortly launching its online survey. Patients, carers and clinicians can submit their uncertainties up to the end of April. Further information can be found on our relaunched website at www.jlapressureulcerpartnership.co.uk. Or you can follow our work on Twitter @JLAPUP."



Richard Morley

Lyme Disease

The Lyme Disease PSP has completed its survey to gather patients', carers' and clinicians' uncertainties about treating Lyme disease. Stella Huyshe-Shires, of Lyme Disease Action, said “Our information specialist has managed to create some order out of the rather daunting 800 odd uncertainties which we collected. The steering group is currently tackling the job of deciding what is within the scope of the exercise. We are looking seriously at every submission in order to ensure that we have not missed any valid questions. As other PSPs will know, this is not an easy task!”



Stella Huyshe-Shires

For further information on this PSP, please contact Stella.Huyshe@LymeDiseaseAction.org.uk.

Preterm Birth

Update from Seilin Uhm, Postgraduate Researcher at the Social Science Research Unit, Institute of Education:

“The aim of the Preterm Birth PSP is to identify and prioritise research uncertainties and outcomes at very preterm birth, which are considered important by both clinicians and service users. Previously, the scope of this PSP was limited to perinatal interventions and treatment only. However, members of the Steering Group agreed to expand the scope to include both pre-natal and post-natal issues. The report for the last Steering Group meeting is available at <http://eppi.ioe.ac.uk/pretermbirth>. We are now exploring the ways to collect research uncertainties from clinicians and service users. The questionnaires, which are currently under development, will be available from February 2012 after a pilot distribution in January.”



To keep up to date with progress, please visit <http://eppi.ioe.ac.uk/pretermbirth>, contact Seilin Uhm (s.uhm@ioe.ac.uk, 020 7612 6532) or follow the Twitter feed @PretermBirth.

Cleft Lip and Palate

Steering Group member, Nicky Kilpatrick, reports:

“It’s full steam ahead for the cleft lip and palate PSP, which kicked off with a one day initial stakeholder meeting last June, in Birmingham. Attended by nearly 50 people we, the steering group, were pleased not only by the almost equal representation of service users and clinicians, but also by the level of engagement, which led to an exciting and productive day. The survey, to identify the unanswered questions in cleft care, was subsequently launched on the Cleft Lip & Palate Association (CLAPA) website in September (www.clapa.com), and, to date, over 200 individuals have contributed around 500 questions. Thanks to the persistent efforts of the Steering Group, questions have been submitted by both service users (comprising 70% of the contributors) and a broad range of clinicians. Now the hard work starts to sift through the questions to identify the confirmed uncertainties. We are grateful to Tom Dobbs and Deepak Chandrasekharan for spending most of their waking hours trawling through the submissions and reviewing the existing evidence. We hope to be ready for the preliminary ranking process by Easter, with the final face-to-face prioritisation meeting planned for the middle of 2012. Whilst there is obviously much work still to do, the steering committee members remain enthusiastically committed to this PSP, the outcome of which will undoubtedly be not only informative but also thought provoking.”



Nicky Kilpatrick

Nicky Kilpatrick is a Paediatric Dentist. Other Steering Group members include Rona Slator and Tim Goodacre (Cleft Surgeons) and Rosanna Preston, from CLAPA. For more information please contact Katherine Cowan: katherine@katherinecowan.net.



Eczema

Tessa Clarke, Senior Clinical Trials Development Manager at the Centre of Evidence Based Dermatology, reports:

“The Eczema Treatments PSP consisted of three phases: a survey to collect the treatment uncertainties from patients and health care professionals; a ranking exercise in which participants were asked to vote for their favourite topics from a list of the most frequently asked uncertainties; and finally, a workshop at which the most popular treatment uncertainties were developed into research questions.

Top 14 Priorities for Eczema Treatments

SHARED PRIORITIES

- What is the best and safest way of using topical steroids for eczema? (Including frequency of application, potency, length of time, alternating with other topical treatments, and age limits for treatments).
- What is the long term safety of applying steroids to the skin?
- What role might food allergy tests play in treating eczema?
- Which emollient is the most effective and safe in treating eczema?

PRIORITIES FROM PATIENTS AND CARERS

- What is the best psychological treatment for the itching in eczema (e.g. habit reversal techniques)?
- Which is the best way to wash, including frequency of washing, water temperature, bath vs shower?
- What are the best and safest natural products to apply to the skin? (e.g. cocoa butter, aloe vera, hemp oil)
- How much does avoidance of irritants and allergens help people with eczema (including washing powders, soap, detergents, pollen, pets, house dust mite, carpets)?
- What is the role of diet in treating eczema? (Including how effective are exclusion diets (e.g. dairy, wheat, nuts, eggs) and how effective are nutritional supplements (e.g. evening primrose, fish oils, iron, marine proteins, vitamins, fatty acids)?)

PRIORITIES FROM HEALTHCARE PROFESSIONALS

- Which is more effective in the management of eczema; GPs, nurse-led clinics, doctor-led clinics, education programmes (How much does supporting and educating patients/carers about treatments and management of eczema help?), or multi disciplinary clinics (with dermatologist, allergy specialist, dietician)?
- Which is safer and more effective for treating eczema; steroids or calcineurin inhibitors?
- How effective are interventions to reduce staphylococcus aureus in the management of eczema?
- Which should be applied first emollients or topical steroids?
- What is the best and safest way of using drugs that suppress the immune system? (including azathioprine, leflunomide, methotrexate, cyclosporine, mycophenolate mofetil, steroids)



Participants at the eczema workshop

“Using online and paper surveys, 493 participants submitted eczema treatment uncertainties. This yielded 1,071 uncertainties, which were refined and collated. Uncertainties known to have been answered by previous research, and those not relevant to the treatment of eczema, were removed, giving a shortlist of 732 uncertainties. In the ranking exercise, 505 participants each selected up to ten uncertainties, and this then provided a ranking of frequency scores for the uncertainties. The ranking was then subdivided into uncertainties prioritised by all participants, and those prioritised by patients and health professionals separately, to ensure adequate representation of all participants’ views.

“The top ranked prioritised uncertainties were then taken to a face-to-face workshop at the British Association of Dermatologists. The workshop was attended by 34 patients, health professionals and researchers. The workshop used the ranked uncertainties, current evidence and personal/professional experience to successfully develop research questions about eczema treatments. These research questions will be publicised and used to guide future research.”

You can find more information about the partnership at www.homeforeczema.org.



Tinnitus



David Stockdale

David Stockdale, Chief Executive of the British Tinnitus Association, reports: “The Tinnitus PSP is now in full swing. We held the Initial Briefing Meeting in London on 7 December. Delegates attended from charities, private companies, hospitals, social service departments, tinnitus support groups and many other areas. One of the aims of the meeting was to get the message out about the Tinnitus PSP and it certainly worked; we’ve already had over 350 online surveys completed

and more are coming in every day. The survey is available online until 28 February 2012 at www.surveymonkey.com/s/JLAtinnitus. It can also be downloaded from the British Tinnitus Association website www.tinnitus.org.uk/JLA.”



The Tinnitus PSP Initial Briefing Meeting

Dementia

The Dementia PSP is the JLA’s newest partnership, which held its first Steering Group meeting earlier this month. The PSP was initiated by Carol Brayne, Professor of Public Health Medicine at the University of Cambridge’s Institute of Public Health, on behalf of Alzheimer’s Society’s Public Health Research Steering Group. The work is being supported by Alzheimer’s Society.

There are currently 750,000 people with dementia in the UK, and this is expected to rise to over one million by 2021. Dementia costs the UK economy an estimated £20 billion per year, more than cancer and heart disease combined. Despite this, dementia research is seriously under-funded – dementia research receives an eighth of the funds going to cancer research. Alzheimer’s Society is dedicated to defeating dementia through research. Research on the effects of treatment is usually led by researchers and funders; this means it can fail to address the questions that matter most to people with dementia. The aim of the JLA Dementia PSP is to identify unanswered questions about dementia treatment from patient, carer and clinical perspectives. The outcome will be a list of 10 top research questions, which have been prioritised by people with dementia, their carers, and clinicians. This will help to ensure that researchers investigate what is important to these groups, and likely to have most impact on people’s lives.

“Alzheimer’s Society is committed to defeating dementia through research,” says Dr Anne Corbett, Research Communications Manager at the Society. “People with dementia and their carers already make a unique contribution to our work. The Society is delighted to be working in partnership with the JLA to bring together the views of people living with dementia and medical professionals, to ensure that future research makes a real difference to patients, carers and doctors alike.”



The Institute of Public Health at Cambridge University is currently recruiting a Research Associate/Senior Research Associate in Stakeholder Engagement to work on this project. For further details, go to www.phpc.cam.ac.uk/jobs/. Applicants should have a working knowledge of scientific and medical terminology, evidence-based healthcare, and clinical trials methodology and basic statistical concepts of meta-analysis. Experience in systematic reviewing and working with clinical trials-related literature is essential.

The primary contact for this PSP is Nicola Hart, Research Support Officer at Alzheimer's Society. For more information, or to get involved, contact her on nicola.hart@alzheimers.org.uk.



The COMET Initiative: Core Outcome Measures in Effectiveness Trials

By Liz Gargon, Project Coordinator

Clinical trials seek to evaluate whether an intervention is effective and safe, which involves measuring outcomes that identify both beneficial and harmful effects. However, it is not easy to decide what these outcome measures should be, and not all comparable studies use the same measures. There is also strong evidence that “outcome reporting bias” – in which only some outcome variables are offered for publication - is a significant problem in randomised controlled trials (RCTs).



Liz Gargon

Another important consideration is that outcomes reported for RCTs may not necessarily reflect what patients want. It is important to redress this, to ensure that RCTs are designed in ways that reveal meaningful answers for patients, if they are to influence healthcare decision-making. These issues are addressed with the development and application of agreed standardised sets of outcomes, known as ‘Core Outcome Sets’, and the COMET (Core Outcome Measures in Effectiveness Trials) Initiative brings together people interested in the development and application of Core Outcome Sets.

Heather Bagley, a mother, attended the first COMET meeting in Liverpool, January 2010

“I was very excited to have attended the core outcomes in clinical trials meeting as it feels like a hugely important and critical way forward in conducting clinical trials. As a parent you trawl through the literature on your child's condition and when you find studies relevant to your child's condition there is no way of comparing the information you find as many studies use such different outcome measurement tools. I am confused as a parent! Goodness knows how practitioners feel when they have to make clinical decisions based on incomparable data. I was overwhelmed by the positivity in the core outcome meeting and felt relieved as a consumer that such an essential issue is finally being addressed.”

Core Outcome Sets should represent the minimum that should be measured and reported in all clinical trials, audits of practice or other forms of research, for a specific condition. This would allow the results of trials and other studies to be compared, contrasted and combined as appropriate, as well as ensure that all trials contribute usable information. The implication is not that outcomes in a particular study should be restricted to those in any given Core Outcome Set, and researchers would still continue to investigate outcomes other than those in the core set.



The development and application of Core Outcome Sets should involve multiple stakeholders, such as healthcare practitioners, regulators, industry representatives, trialists, researchers, patients, carers and the public, in order to determine what should be “core” in any given condition. Examples exist where the involvement of patients in the development of Core Outcome Sets identified an outcome important to them and that might not have been considered if the outcome set had been developed by practitioners alone. However, despite increasing recognition of the importance of incorporating health service user opinion in the development of Core Outcome Sets, their involvement has been limited to date. We need to work collaboratively with patient-interest organisations to promote the aims and principles of the COMET Initiative and work with Core Outcome Sets developers to improve patient engagement throughout the process.

The COMET Initiative has developed a database of studies relevant to the development of core outcome sets for use in clinical trials, where researchers, patients and the public can access

information on outcomes recommended for clinical research (www.comet-initiative.org/studies/search).

Having established and raised awareness of the COMET Initiative, we are working with research funders to find ways to fund the development of core outcome sets and promote their uptake.



Further details about the COMET Initiative can be found at www.comet-initiative.org. You can email e.gargon@liv.ac.uk or follow us on Twitter @COMETinitiative for more information.

Association of Medical Research Charities and the JLA

By Dr Sophie Petit-Zeman, Adviser, Public Involvement & Engagement, AMRC



The Association of Medical Research Charities (AMRC; www.amrc.org.uk) is a membership organisation of the leading medical and health research charities in the UK. The AMRC currently has 125 member charities responsible collectively for about one third of UK public expenditure on medical research - over £1 billion annually.

AMRC members (a full list can be found here: <http://www.amrc.org.uk/our-members>) work across the entire spectrum of medical research and represent a major spread of types and size of charity. Our three largest members are the Wellcome Trust, Cancer Research UK and the British Heart Foundation, while others include far smaller organisations set up and led by patients and/or carers.



Sophie Petit-Zeman

As a member of both the JLA's Monitoring and Implementation Group and its Strategy and Development Group (SDG) since they were formed, I have tried to ensure that the JLA knows what the AMRC world is up to, and vice versa, enabling our member charities to get involved in JLA partnerships and other work, where relevant. Indeed, the first JLA PSP was spearheaded by Asthma UK, and a further fifteen or so AMRC members have been involved with the JLA since then. Emma Malcolm, Chief Executive of AMRC member charity Prostate Action was recruited onto the JLA SDG after infusing the prostate cancer PSP with her boundless enthusiasm for the JLA model - it



could have no better advocate. AMRC has also held joint events with the JLA, covering issues from links with the drug industry, to research commissioning and patient involvement. We were delighted that Sir Iain Chalmers, one of the JLA's "founding fathers," has twice been one of the judges for the AMRC's Science Communication Awards.

I regularly update AMRC members about the JLA's work through our electronic member briefing. Such communication is sometimes simply about spreading information, or may involve specific requests where, for example, JLA PSPs are seeking partners or wanting to broaden their reach when gathering uncertainties. We are looking at how best to enhance the relationship between the JLA and our members – if you would like to know more, or indeed if you have a message to share with the medical research charity world, do get in touch. I am available on s.petit-zeman@amrc.org.uk or give me a call: 01732 750 869.

EVENTS

Health Services Research Network and Health Foundation Conference

The Health Services Research Network and Health Foundation Conference took place in December 2011. In response to the challenges faced by the health service, it was an opportunity for the health services research community to meet and consider how to safeguard health services research and to continue to make a contribution in the new NHS. The meeting explored ideas and concrete suggestions were made on the way forward for the health services research community. The JLA's work was presented in four presentations and table discussions. Sally Crowe said of the event, "It was a really good opportunity to hear researcher views on the JLA approach to identifying important unanswered questions, and there were some good methodological challenges as well."



Sally Crowe

IN PRINT

Lophatananon, A., Tyndale-Biscoe, S., Malcolm, E., Rippon, H., Holmes, K., Firkins, L., Fenton, M., Crowe, S., Stewart-Brown, S., Gnanapragasam, V. and Muir, K. (2011) "The James Lind Alliance approach to priority setting for prostate cancer research: an integrative methodology based on patient and clinician participation". *British Journal of Urology International*, 2011, Vol 108, Issue 7, pp. 1040–1043.



The purpose of the present paper is to describe the methodology exemplified by a recent JLA partnership investigation into the uncertainties that surround the treatment of prostate cancer, the major male cancer which kills over 10 000 men in the UK every year. The authors explore the experience of the JLA Prostate Cancer PSP, and the strengths and weaknesses of the methods it employed. The exercise yielded a list of 11 uncertainties, as set out by patients and clinicians dealing directly with the disease. Prostate cancer research has gained a great deal of attention during recent years. It is hoped that this list of uncertainties – obtained specifically to highlight the most pressing clinical needs as perceived by patients and clinicians working in the field – will help funding



organisations and researchers themselves to set their research priorities. By integrating quantitative and qualitative methods, the exercise has enabled the authors not only to gather many validated uncertainties but also to understand the rationale behind them. Read the full article at www.lindalliance.org/Publications.asp.



Uhm, S., Liabo, K., Stewart, R., Rees, R. and Oliver, S. (2012) "Patient and public perspectives shaping scientific and medical research: panels for data, discussions, and decisions". *Patient Intelligence* 4; 1. This paper explores the role of patient panels for shaping research for health, scientific research about health and illness, and applied medical research. After examining the history and purposes of involving patients in discussions and decision making for research, it outlines the expertise and skills required if panels are to be successful. It makes direct reference to the JLA and the JLA Guidebook. The full article is available on http://www.dovepress.com/articles.php?article_id=9064 with open access.

Petit-Zeman, S. (2011) Stroke Survivors Have Their Say on Research Priorities. *Society Guardian*. 29 November 2011. p36.



This article describes the JLA Life After Stroke in Scotland PSP, from its work to engage patients, carers and clinicians to identify treatment uncertainties, to the prioritisation process and final workshop. It is available online at <http://www.guardian.co.uk/society/2011/nov/29/stroke-survivors-highlight-research-priorities?>

Coulter, A. (2011) *Engaging Patients in Healthcare*, Open University Press
This evidence-based guide provides a comprehensive overview of patient engagement and participation in healthcare. It has been written for all those who want to understand the various ways in which patient and public engagement can contribute to better health outcomes. It refers to the JLA as an example in its chapter on participating in research, which looks at the various ways in which patients can contribute to research, both as study participants, and as contributors to the research process, including determining research priorities. For more information, go to <http://mcgraw-hill.co.uk/html/0335242715.html>.



ON THE WEB

Stay up to date with our work at 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, visit our online Guidebook:



www.JLAguidebook.org. The Guidebook features examples of existing PSPs, including documents and templates to download and use.

You can also follow us on Twitter: www.twitter.com/LindAlliance.



CURRENT AFFILIATES

The JLA currently has 437 Affiliates, most of whom are listed on our website. The 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 about 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 to sign up.

Dr Alessandro Liberati

Newsletter Editor Katherine Cowan remembers Alessandro Liberati, who died on 1 January 2012, following a long battle with multiple myeloma.

Alessandro Liberati, Associate Professor of Medical Statistics and Biometry at the University of Modena, had been leader of the Italian Cochrane Centre since 1994, and was a major figure within the evidence-based healthcare community.

I was fortunate enough to work with Alessandro in November 2011, after he invited me to speak at the Italian Cochrane Network's annual conference in Rome. The general theme of the meeting was how to make clinical research more valid and appropriate for patients, and he specifically asked me to talk about how the JLA involves patients in research priority setting. Introducing the conference, Alessandro lamented the scarcity of research funding available in Italy, and a lack of coordination. He spoke passionately about the importance of relevant research, including the re-alignment of patient-orientated and commercial and academic research. A recent letter he wrote to the Lancet about this issue has been published on the Cochrane library website:

www.thecochranelibrary.com/details/editorial/1431131/Need-to-re-align-patient-oriented-and-commercial-and-academic-research.html.

I really enjoyed spending time with Alessandro and his team, who all made me feel very welcome in Rome. He was so friendly and approachable, and very funny. On the evening before the conference, Alessandro hosted a wonderful meal at a restaurant in the university district of the city. He brought with him a special bottle of wine, which, he explained, he had acquired when Berlusconi came to



Laura Amato, Vanna Pistotti, Katherine Cowan and Alessandro Liberati, November 2011



power. He had been saving it for the day the controversial president stepped down. Berlusconi had resigned the day before, so after a short and happy speech from Alessandro, the bottle was opened, and shared between the 20 or so people gathered around the table. However, he retained a small amount of the wine in the bottle, which, he said, he would hold back just in case Berlusconi decided to seize the reins of power again. He made everyone laugh and was such a warm and engaging host.

It was so obvious that night and at the conference the next day that Alessandro was not only highly respected but also much loved by his colleagues. This has been further reinforced by tributes paid on the internet, describing him as an inspiring leader, a hero for evidence-based medicine, a champion for patients as partners in research, and a beautiful person. I feel really privileged to have had the opportunity to spend some time with him, and on behalf of the JLA would like to extend my deepest sympathies to his family, friends and colleagues all over the world.

www.cochrane.it.

www.cochrane.org/alessandro-memory-book

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. In the Publications section you will find a downloadable bibliography, along with an archive of useful JLA publications.

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 March 2012.

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