

Action on Puerperal Psychosis News

Volume 7:1, Spring 2007



Welcome back...

by Jackie Benjamin

It has been four years since the last APP newsletter. We have had difficulties in finding someone with capacity to take on the job of producing the newsletter since I started working elsewhere. Research has been continuing however, and Ian Jones, Jess Heron and I have been keeping in touch to work out the way forward. We now have administrative support from the Cardiff University and Jess Heron, now Research Fellow at The University of Birmingham, has agreed to edit the Newsletter. I hope you will find the content interesting and continue to support Action on Puerperal Psychosis.

Remarkably little is known about puerperal psychosis in terms of causes, likely outcomes and best treatments. I believe that APP is a vital project and that those involved in running it have a unique interest in and attitude towards puerperal psychosis. We recognise the importance of a variety of different approaches to research. I am particularly excited about the research which Jess is embarking upon which will involve listening to and analysing the experiences of women and their partners. I think this will be important in influencing future policy makers who have to make choices about what services and treatments should be available.

THE APP IS 10 YEARS OLD

Action on Puerperal Psychosis was launched in 1996 by Professor Ian Brockington and Jackie Benjamin. Prof Brockington treated women in his clinic at the Queen Elizabeth Psychiatric Hospital in Birmingham for over 20 years and was a founder of the Marcé Society for Mother and Baby Mental Health. Jackie is a lawyer who experienced episodes of PP after the birth of both of her sons. She began working as the project's co-ordinator when her sons were small. They recognised the need for greater research into the causes, but realised that this was hampered by the comparative rarity of the illness. They set up the 'Action on Puerperal Psychosis' network in order to facilitate research and to act as an information resource for women keen to keep abreast of current research into puerperal psychosis. From an original core of 50 women members, we have now grown to a membership of over 400 women living throughout the UK.

CHANGES TO THE TEAM: WHO AND WHERE WE ARE

With a number of key individuals moving from Birmingham to Cardiff University, the decision has been taken to move the APP to Cardiff. We have a new email address and in the near future our new website will be up and running. The Birmingham web site will continue to work but link to the new site.

Dr Ian Jones

Ian has moved to the Department of Psychological Medicine at Cardiff University, where he is a Senior Lecturer in Perinatal Psychiatry and Consultant Perinatal Psychiatrist. He continues to work closely with the Mood Disorders Research Group in

Birmingham. A number of exciting projects are underway which will be described in more detail in this and future issues.

Jackie Benjamin

Jackie returned to full time work with the Law Society in December 2001, in order to contribute more to family finances. We thank her for her dedication and the immense amount of work she has contributed over the years. She continues to be actively involved on the steering committee of the APP and in campaigning for PP research and changes in healthcare policy. Jackie has become a lay member

of the Executive Committee of the Section for Perinatal [*i.e. related to pregnancy and the post-natal period*] Psychiatry of The Royal College of Psychiatrists. This is a Committee which meets throughout the year to organise specialist training and comment officially upon a variety of matters, such as: the training of psychiatrists; the way consultants are appointed; and upon NHS healthcare guidelines.

Dr Emma Robertson Blackmore

Emma moved to Toronto, Canada, in 2002 to a postdoctoral position investigating postpartum depression. She married Tony Blackmore in 2004, and moved to the USA. She is now an Assistant Professor in the Dept of Psychiatry at the University of Rochester in New York, studying mood disorders triggered by pregnancy. She is still closely involved with the work of the APP and hopes to set up similar studies in the States.

Dr Jessica Heron

Jess completed her PhD early this year, and has joined the Department of Primary Care and General Practice at Birmingham University as a post-doctoral research fellow in mental health. She will be setting up a project to examine how health services can meet the needs of women (and their families) who experience an episode of PP (*see the 'how can I help' section*). Jess has agreed to take over editing the APP newsletter.

Professor Nick Craddock

Nick has moved to the Department of Psychological Medicine at Cardiff University, where he is heading the mood disorders research team. Under Nick's leadership the team has gone from strength to strength, and has been successful in obtaining grants and publishing scientific papers. Nick continues to work with Ian on the molecular genetic basis of puerperal psychosis.

Professor Ian Brockington

Professor Brockington officially retired on 30 September 2001 but has continued to publish and speak at international conferences. Since 'retirement' he has published a number of papers on mother/baby bonding and two books. The first book concerns the Birmingham Interview for Maternal Mental Health, which is an interview he developed for assessing mental health problems. The second book entitled 'Eileithya: The Organic Psychoses of Pregnancy, Parturition and the Puerperium' examines mental symptoms with physical causes such as infection, eclampsia and other medical disorders. These psychoses are rare today in the developed world but were very common before the use of antibiotics. They are still important in the 'third

world' where most of the world's children are born. Professor Brockington self-published the books, printing and binding them himself. He is currently working on a book about Menstrual Psychoses where episodes are linked to the menstrual cycle.

Once his current project is complete, he plans to start work on a book about puerperal psychosis which he now prefers to call "puerperal bipolar disorder".

Christine Murdoch

Christine continues to work part-time as a Research Associate in Cardiff. She is currently interviewing participants for the mood disorders study that have responded to the Stephen Fry publicity (described later in this issue).

Dr James Walters

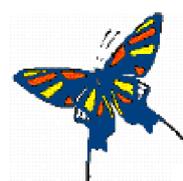
James has recently joined the group as a clinical lecturer in psychiatry. He trained in medicine at Southampton University and in Psychiatry at Cardiff University, the Institute of Psychiatry in London and in Sydney, Australia. James returned to his hometown of Cardiff two years ago and is working in the Department of Psychological Medicine developing a further interest in the link between genes and cognition in bipolar disorder and schizophrenia. Together with Ian Jones, James has gained funding to conduct a study of the monthly variations in symptoms of women with bipolar disorder and hopes that a number of women in the APP will be willing to take part in this project (*see the 'how can I help' section*).

Sian Caesar

Sian is a Research Associate in the Mood Disorders group in Birmingham. Sian will be conducting telephone and face-to-face interviews with new APP members for the clinical and molecular genetic studies of puerperal psychosis.

Liz Upadhyay

Liz has agreed to act as the new contact for the APP. She is a medical secretary in Cardiff, and will be able to direct your queries and questions to the rest of the team. Warm thanks are due to her for this invaluable support.



RESEARCH UPDATE

Genetics Studies

One of the main avenues of research our group has been following is trying to find genetic factors that make some women vulnerable to episodes of severe illness following childbirth. The goal of this work is to improve treatments, identification and advice for those at high risk of PP. The work on postpartum illness is an important part of the more general mood disorders work of the group.

Through fantastic help from women in the APP panel we have been able to conduct some important studies and are making progress in the difficult task of understanding more about why some women become ill at this time.

We have published studies that show that a vulnerability to episodes of illness following childbirth runs in families, and have published work that has looked at the involvement of a number of specific genes.

We have identified a number of chromosomal regions that tend to be shared by those that experience PP and investigations are ongoing into genes in those areas. We have also been concentrating on examining individual genes that code pregnancy and mood related hormones or receptors, such as oestrogen, serotonin and oxytocin, and genes that have been suggested to be involved in other psychiatric conditions. This all involves a huge amount of work from a large number of people in the group but there is a considerable amount of work that remains to be done. Things are looking encouraging, but we are still some years away from advances that may really make a difference to women's lives.

The work done by the group is reflected in a large number of papers that have been published in scientific journals. We hope to discuss some of the papers published in detail in future editions of the newsletter.

Living with Puerperal Psychosis

One of the avenues of research that the team would like to pursue further are studies looking at the experience of puerperal psychosis. Emma conducted in-depth interviews with 10 women from the APP and a number of key themes arose out of the interviews.

All of the women interviewed viewed childbirth as the precipitant of their illness, predominantly viewing it as biological or hormonal, with traumatic births or stressful pregnancies as further precipitants. Women viewed PP as different from other forms of mental illness, requiring separate and specialised forms of treatment.

Many described a lack of experience in health professionals compounding their fear and sense of isolation. Lack of control over treatment and their lives was discussed by many women, who felt anger that they, and their families, were sidelined from decision-making processes. Many women talked of the lack of support in place for husbands – who either became responsible for looking after their partner and baby or was separated from them.

A sense of loss and, for some, guilt arose as a key theme at being unable to fulfil the role of a new mother. An interesting issue described was of losing the privilege to feel 'normal emotions' without worrying, or others worrying, that this was a sign of illness.

Those interviewed described that relationships with friends and family are often strained following an episode. They felt there was a correlation between friends' reactions and a previous awareness of psychiatric illness. For some the use of humour was useful, while in other families the illness was not spoken about and women felt denied the opportunity to discuss worries.

For most, it was described as a 'life changing experience', forcing a struggle with self identity, but most felt that they 'regained their old sense of self', and gained greater confidence, self awareness, and a sense of empathy with others.

Following on from this research, Jess is conducting interviews to examine how health professionals can improve the experience of obtaining help for, and recovering from, PP. She would be very interested in any comments you have. (j.c.heron@bham.ac.uk)

Risk of puerperal and non-puerperal recurrence of illness

We have also studied the risk of further episodes of illness for a woman that has suffered an episode of PP. As part of her PhD, Emma took the lead in conducting the largest study to date into risk of recurrence.

We found that after experiencing an episode of PP, women had a significant risk (around 57%) of becoming ill following a subsequent delivery, *but*, we also found a high risk of experiencing an episode of illness unrelated to childbirth. Our findings indicate that advising women to avoid future pregnancies if they wish to avoid further episodes of illness might not be appropriate. The findings and implications are complex however, and will be discussed in more detail in a future newsletter. We are planning work to try to understand the factors involved in why some women have further episodes of illness while others just have one puerperal episode. This work will be important in advising people on their individual risks and on ways of reducing the risk of recurrence.

Obstetric factors associated with PP

We are keen to understand more about why following some pregnancies women experience PP, whilst the same women remain well after future pregnancies. Emma compared deliveries that were affected and unaffected by PP. We found that primiparity (i.e. being a first time mother) and experiencing a medical complication during delivery were significant risk factors for PP.

The next step is to design studies that can explore what biological and psychological mechanisms could account for these findings.

Early symptoms of Puerperal Psychosis

Jess examined the earliest symptoms reported by women in their episode of PP. Prior to this study it was believed that symptoms did not occur before days 3-4 following delivery. Most women in our sample felt that, looking back, they could notice symptoms beginning on day one, and some 10% felt that they began to feel more 'elated or strong and important' over the last trimester of pregnancy. This has implications for the types of hormones we consider as good candidates for a role in PP.

The most commonly recalled symptoms were feeling 'excited, elated or high', feeling 'more active and energetic, 'talking more or feeling chatty', 'not being able to, or needing to sleep', and other symptoms such as 'feeling anxious or fearful' or 'confused, unreal and in a dream world.' Health professionals rarely ask about these kinds of symptoms, even in women at very high risk of PP episodes. Indeed they are likely to consider that such women are coping 'ultra well' with pregnancy and the demands of new motherhood. The team has submitted a paper to a journal suggesting that health professionals be aware that these feelings could mark the beginning of a mood disorder and deserve closer scrutiny.

The Highs

In her PhD Jess examined symptoms of high mood and elation in postpartum women (who *did not* develop an episode of PP). She found that there was a spectrum of severity of 'bipolar-like' symptoms in the normal postpartum population and that these symptoms were much more common in the first week postpartum than during pregnancy or later in the postpartum. The more extreme these high mood symptoms were, the greater the chance the women would suffer a postnatal depression.

She examined a range of risk factors for postpartum high mood. As in PP, primiparity (first delivery) was a risk factor, as was a previous history of minor mood disturbance and a family history of high mood or depression. Other interesting findings were reported with personality traits and obstetric factors that need to be replicated in larger samples. Interestingly, high

mood (even though it was associated with later depression) did not adversely affect the mother baby bond.

It is hoped that studies of mild symptoms can give insights into risk factors and mechanisms that should be investigated in PP, and help to inform women at high risk on ways of minimising their chances of developing an episode.



PRESENTATIONS

One of the important ways in which we can let other scientists and clinicians know about what we are doing to understand more about Puerperal Psychosis is by presenting our work at scientific meetings and conferences. We have presented talks on PP at a large number of meetings and in future editions of the newsletter we hope to give you more details about some the work presented.

FUTURE STUDIES

We are very pleased that our Wellcome Trust Programme grant has been funded for a further five years. This grant funds the important research the group conducts into the genetic and environmental causes of mood disorders and ensures that work to find the causes of postpartum mood disorders, with your help, can continue.

The mood disorders group is also excited to be part of the Wellcome Trust Case Control Consortium study of complex genetic diseases. This very large study of eight diseases, of which bipolar disorder is the only psychiatric illness being considered, will obtain data from over half a million genetic markers and is likely to result in a number of exciting findings. The study will include over 2000 individuals with bipolar disorder and we are pleased to note that women who have suffered an episode of PP are well represented: 200 being included in the study. This important project is the largest of its kind in the world and we will bring you more details of the results in future newsletters.



Stephen Fry with Prof Nick Craddock

STEPHEN FRY VISIT

A number of you may have seen the recent Stephen Fry documentaries shown on the BBC about his bipolar disorder. The programmes featured the work of our group and Ian and Nick were interviewed by Stephen in the documentary.

Stephen volunteered to help with the bipolar disorder molecular genetic research and was interviewed and gave a sample of blood.

The programmes also featured the story of Gaynor, a member of APP, who did a fantastic job of describing what she went through during her puerperal psychosis episode. Gaynor had to make a difficult choice with regard to trying for another baby and, given the very high risk of her suffering a further episode of postpartum illness, she chose not to get pregnant again.

The programme showed her making this difficult choice - clearly the right decision for her and her family. Due to the limited time available, however, the programme did not go on to explore how for some women, even at very high risk of a further PP episode, having another baby may also be an appropriate choice. We would not want women watching the programme to feel that a woman who has suffered with PP should never have any more children. What is important is that the decision regarding further children is made with all the available information about risk and how this risk can be minimised.

PUERPERAL PSYCHOSIS POLICY

In the past few years there have been some important documents published which have significant implications for the treatment, by the health service, of women with Puerperal Psychosis.

These include the Confidential Enquiries into Maternal and Child Health and a number of guidelines from the National Institute of Clinical Excellence (NICE). NICE guidelines have been published on Bipolar Disorder and on antenatal care and, more importantly, NICE guidelines on antenatal and postnatal mental health are due shortly.

A draft of the latter was published last summer. Jackie and Ian, who sit on the Royal College of Psychiatry's perinatal section executive, have been involved in drafting the response of the Royal College of Psychiatrists, raising a number of issues which were not dealt with adequately in the draft. The importance of these guidelines can not be overemphasised as they will be the basis upon which the NHS will plan services in the coming years - we will review the final published guidelines in future newsletters.

UPDATE ON IMPORTANT ISSUES (FAQ)

In future editions we hope to keep you updated on current thinking concerning some of the important questions in PP, looking at the latest evidence regarding frequently asked questions such as: 'What can I do to prevent puerperal psychosis recurring after a subsequent pregnancy?' and 'How likely is it that I will have another episode following another pregnancy?' *If you have any other questions that you feel would be relevant to many in the APP, please contact Jess or Liz.*

WOMEN'S VOICES

In the next issue we would like to balance out our voices with ideas, short articles, poetry and contributions from you. *If you have anything you would like to submit, please contact Jess at j.c.heron@bham.ac.uk.*

PUERPERAL PSYCHOSIS RESOURCES

In the next issue we hope to include a section on puerperal psychosis resources, websites and book reviews.

In the meantime, the APP website lists some useful organisations.

<http://www.neuroscience.bham.ac.uk/research/app/>

The following link to the department in Cardiff details some of the group's work.

http://www.cardiff.ac.uk/medicine/psychological_medicine/research/mrc_coop/current_research/bipolar/bipolar_affective_postpartum_puerperal_psychosis.htm

We should also mention the following useful website, which has been set up by a member of APP: www.ppinfo.org.uk

HOW CAN YOU HELP?

The pathway to care & support on recovery in PP

Jess is conducting a study, interviewing women who have recovered from an episode of PP and their partners about their positive and negative experiences of gaining health service help for PP and gaining support on recovery. We hope that through these interviews, we can suggest ways to improve health services for women who have an episode of PP and their families.

The interview takes about 90 minutes and 60 minutes with partners. The interview can take place in your own home (or an alternative venue can be arranged if preferred) at a time convenient to you.

If you have experienced an episode of PP in **the last 5 years**, and would like details of the study, please contact Jess on j.c.heron@bham.ac.uk or 0121 414 3764.

Clinical and Molecular Studies

With the excellent news that our Wellcome Trust programme grant has been funded for a further five years we will shortly be in a position to begin again to conduct interviews with women that have suffered with episodes of PP. Many of you will already have helped by being interviewed and giving a sample of blood. If you have not yet taken part and would like to, please contact Sian Caesar on E.S.Caesar@bham.ac.uk or 0121 678 2361. For women that live a long way from Cardiff or Birmingham we may also be able to arrange an interview over the phone, so please still get in touch where ever you live. Taking part involves an interview lasting about 90 minutes about symptoms of PP and giving a sample of blood.

Daily symptoms project

Dr James Walters is conducting a study to examine how mood symptoms vary from day to day. Taking part will involve filling in a short questionnaire (3-5 minutes) every day for 3 months. He would like to hear from any woman who has had a diagnosis of bipolar disorder or puerperal psychosis.

For full details of the study contact Dr James Walters (email: waltersjt@cf.ac.uk , tel: 02920 745833) or Ms Elizabeth Upadhyay, (tel: 02920 742284).

OTHER MATTERS

Sphinx Theatre Company

We have been contacted by The Sphinx Theatre Company (<http://www.sphinxtheatre.co.uk/>) who have been given Wellcome Trust funding to develop a play, inspired by the novella 'The Yellow Wallpaper'. The play will consider some of the issues surrounding puerperal psychosis. They would like to conduct and record some interviews with women who have suffered from a puerperal psychosis, in order to inform the piece. If you would like to be involved contact Rachel Barnett on 07977 935 860 or ray_barnett@ntlworld.com



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Our web page is at: www.neuroscience.bham.ac.uk/research/app/

We are sorry that we are unable to give advice on individual cases. Our project aims to further research into puerperal psychosis. For details of organisations that can offer support, please see our web site.

Please let us know if you change your address or telephone number, or if you have received this newsletter in error.

ACTION ON PUERPERAL PSYCHOSIS NEWSLETTER

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