

Seroxat Newsletter

Contents

Internet Developments	1
United States News	2
Medicines Control Agency	2
Media	2
Manifestos	3
Manifestos	5
Ballot Form	5
Letter to MP	6

Welcome to the first Seroxat Users Group newsletter.

The Seroxat Users Group is a self-help and mutual support group which will provide information and be a public focus group for the users and former users of Seroxat and their families, including those bereaved following the suicide of a family member while using Seroxat. The Group will be a self-administered and organised group independent of the litigation.

A number of people have expressed an interest in running the group. Indeed such has been the response that

we have had to organise an election! It is intended that the Group should have a committee of four. It was felt that too large a committee would make the organisation difficult. You can find out how to cast your votes on page 5.

To facilitate an efficient Group where the actions of it and its committee are liable to public scrutiny it was thought that those to be considered for election would be only those who have returned their questionnaires, who do not insist on public anonymity and to assist in reducing overheads, by reducing the costs and increasing the

speed of communication, be e-mail and internet accessible. There is an enormous and growing amount of information on the drug and related matters on the internet. Hugh James will prime the Group and continue to support it, for instance with IT support and production of the newsletter. It is likely that the Committee will ask for donations to facilitate the Group's administration costs, such as postage, stationery and telephone bills. Hugh James will continue to correspond directly with its clients about the litigation and their specific cases.

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Extra Developments

Internet

Derek Scott has set up a message board for Seroxat Users at www.ds010a5436.pwp.blueyonder.co.u.k It has many interesting items on it including a series of correspondence between Derek, MP's and Government Departments.

Much information can also be gleaned from www.socialaudit.org where Charles Medawar of the charity, Social Audit, has been campaigning for several years against not only Seroxat but drugs of the SSRI (Selective Serotonin Re-Uptake Inhibitor) class generally.

United States News

US attorneys (with whom Hugh James is working) have succeeded in obtaining a temporary court order to ban Glaxo SmithKline from advertising Seroxat on television with the motto "non-habit forming". The Judge will hold a full hearing in October to consider the matter further. However not only is the Judge's decision criticised by GSK but the US Food and Drugs Administration also argues that the court exceeded its powers.

There is no 'direct to patient' advertising in the UK, but Hugh James is considering various remedies to secure changes to the patient information and data sheets. This involves the possibility of Judicial Review of the Medicines Control Agency if it continues to decline to act in response to the substantial evidence of dependency.



SEROXAT Tablets

30 TABLETS

0



Mark Harvey
Partner at Hugh James
Solicitors

Future Developments

Medicines Control Agency

At the first meeting of the Group it was decided that all members should write to their local MP's along the lines of the letter attached at the end of this newsletter (It need not be copied ex-

actly). The MP has an obligation to respond to the letter within 14 days and should be directing their constituents' concerns to the Department of Social Security and then the Medicines Control Agency (MCA). Those Group members who have not written are

encouraged to do so. Hugh James has written to the MCA inviting it to take the evidence offered by its clients of the withdrawal problem. To date the MCA has only ever accepted Adverse Drug Reaction reports from doctors.

The Hugh James
Seroxat Team

Mark Harvey
Karishma Jasani
Marlene Hart

Please address all enquiries to Karishma and Marlene.

Media

Mark Harvey of Hugh James continues to invoke media interest wherever possible to generate public pressure on GSK and the government. If any Group members have any links with

any media would they please let Mark know through his secretary, Marlene.

It would be helpful however to ensure consistency of approach and efficiency of useage if interviews could be channelled through

Hugh James, who can offer the use of a Public Relations company to manage the media effectively and with as little intrusion to members as possible.

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Manifestos

Those who wish to be considered for the Seroxat Users Group Committee have put forward their manifestos.

You may vote for up to four people.

Instructions on how to vote can be found on page 5.

1. Paula Boddington

I would like to serve on the User's Group because I feel passionate about how so many thousands of people have been made to suffer, unnecessarily and without proper acknowledgement of what they are going through, by the duplicity of the drug companies.

About me: my background is as an academic philosopher, specialising in ethics and in particular medical ethics, which again gives me a particular interest in the issues. I have worked in universities both here and in Australia and worked on committees and working parties on ethical issues for the Australian Department of Health, and more recently for the Kings Fund in London. I have a number of publications on medical ethics in a variety of forms. I have experience of committee work in the university, government and voluntary sector. As president of an Australian preschool association I led a campaign against its closure involving extensive lobbying and work with all areas of the media. I am the mother of two primary school aged children and hope to be doing part time research work which will leave me time to devote to the committee.

2. Terry Burton

I would like to sit on the User's Group committee as I consider, that my situation, whilst no worse than anyone else's who is frightened of what is going to happen to them, is probably one of the longest takers and heaviest doses that I have come across, so I have more interest than most. I have also tried to come off the drug on three occasions. All failed miserably with disastrous consequences.

Also I have served on numerous committees in the voluntary and charitable sector, and they can be very slow moving if not downright stagnant which must not be, so it needs strong personal commitment which I have. I was one of the 'first five' to be at the morning launch to the press and media, prior to the afternoon meeting in London a short while ago.

3. Karen Harries

My single motivation for wishing to be part of the User Group Committee is to help prevent even one person from going down the road I've been on.

I'm now 38 and a single parent of 3 children (nearly 13, 11 and 9). I used to be a Senior Manager in Donor-Aid Purchasing, which included a fair amount of international travel. The last three years before I gave up work was based on purchasing management and strategic purchasing within the NHS. As a result of an abusive marriage which culminated in a number of breakdowns I was diagnosed as suffering from clinical depression. My GP proposed Seroxat as a non-addictive solution. As the years have unravelled my problem has been two-fold, overcoming the depression (for which there has been professional help) and coping with the withdrawals. I am still on Incapacity Benefit but thanks to your meeting am now finally weaning myself off Seroxat. I had reached a plateau of 10mg a day and was not aware (nor was my GP) of the syrup alternative.

I am currently studying an Open University module on "Understanding Health and Social Care". Once I am free of the medication I will go back to work and hope to be able to use this as a stepping stone into a new area of work.

My experience is available to the Group regardless as to whether I am voted onto the Committee or not. I would summarise my key experiences as being my previous experience of red-tape, beauracacy, committees (especially creating new groups, Terms of Reference etc), marketing, promotional activity, an unemployed person, a single mother and an addict (in no particular order of priority).

4. Andrew Isaac

I would like to be considered for a place on the committee. I feel I am a good candidate for the following reasons: -

I have been through the horrendous withdrawal myself, and know how terrible it can be for the person

withdrawing and for family and friends. Also I am unusual in that my withdrawal has been so long lasting.

I have completed 3 years of my medical training and once fully well intend to complete the rest of my course. I have a good understanding of the pharmacology of these drugs, and how to withdraw effec-

tively and the various side effects they can have etc. As the User Group may be a long term project it may be useful to have a medical spokesperson. Having said that I m not suggesting that I know any better than anybody else, but I will have access to the right resources to check things out should it be deemed necessary.

(Continued on page 4)

(Continued from page 3)



Karishama Jasani
Paralegal at Hugh James
Solicitors

I am also very well informed on matters of alternative health, which some people will be interested in, and will help some, but not all people. People who are withdrawing can become very desperate and there is a lot of misinformation out there. I can help some people sort out what may be useful from the "snake oil".

I have good communication skills and have completed trainings in Ericksonian Hypnosis and Neuro Linguistic Programming. Both these disciplines place a high emphasis on good, clear communication, and, artfully so. I feel I speak well in public.

I have a wicked sense of humour! I feel this is very important, more so than anything else I have written here. With dealing with various different people like the press etc a sense of humour is important as it can lighten situations and ease tension while getting people on side.

I don't embarrass easily and am quite happy to talk about the embarrassing stuff, e.g. erectile dysfunction, anorgasmia etc.

I keep up to date with the latest happenings on Charles Medawars Social Audit Website, which at the moment is the most up to date info you can get. I also get e-mails from Ann Blake Traceys Drug Awareness site.

I make a great cup of coffee and have a sticky out belly button (ok I'm lying about the belly button! But I do a great Frank Spencer impression!)

5. Christopher Keegan

My name is Christopher Keegan aged 44 years of Market Drayton, Shropshire. I would like to sit on the Seroxat Users Group Committee. In November 2001, I lost my son to suicide. He was using Seroxat for 26 days. I have sat on Committees in the past and I feel I could be of assistance to the group.

6. Maddie Leighton

Aged 45. My Seroxat withdrawal horror story may differ a little from many of you but is not an isolated case. As well as the hideous physical withdrawal symptoms which still plague me to a lesser degree today, such as vertigo, balance problems, memory lapses, vivid nightmares, Tinnitus, jaw clenching (six broken teeth to date) and the involuntary jerking of limbs (like electric shocks). I had episodes of hypomania in 1998 and 1999 both during the reduction in dosage process towards discontinuation (which for me was far too quick). Due to this in 1999 I was labelled manic-depressive. I have fought against this diagnosis, discontinued (very slowly) the many drugs I was addicted to, refuse to see any psychiatric staff except a clinical psychologist and now take no psychotropic medication whatsoever. My (then) Psychiatrist now has me labelled as 'recurrent depressive disorder [symptoms mild]' although he hasn't had the decency to inform either myself or my GP of this, I only found out when receiving my notes as part of an appeal when I was disallowed DLA last December. I have not had an episode of Hypomania since 1999 and suffered my last bout of depression in July 2000. I can state that despite many years of depressive episodes (due to post natal depression or the underlying Coeliac Disease condition of which I was not diagnosed until I was 40) I was never suicidal before taking Seroxat, but almost permanently suicidal during and after. I have worked with Wiltshire and Swindon Users Network as User Involvement Worker (Mental Health) and supported Service Users at Primary Care Trust planning and implementation meetings and during the formulation of the National Service Framework, and also arranged a series of Service User meetings called "Our Time To Talk" when Primary Care Trust Mental Health professionals are invited to attend to update Service Users in changes to services, but primarily to LISTEN to Service Users. I did that for some time before regaining my own business as part of my divorce settlement, which I now run full time. I'm also a trained Buildings Auditor with Wiltshire Access Consultancy and audit buildings/advise on access issues in public buildings for the Disability Discrimination Act coming into force in April 2004, and am also their part-time administrator. Once a month I attend a group called SURF (Service User Research Forum) which was formed after a training course on Research and Development and Clinical Audit, run by (but led by service users) Avon and Wilts Mental Health Partnership Trust. Last month our opinion was sought on 34 research proposals for next years funding, from a purely service user perspective, and am assured by Dr Tony Soteriou the head of R&D that our group is unique in the country but working towards being the norm. Opportunities to participate in research projects has been slow to come but is our ultimate

aim along with the retraining of NHS staff. Until recently I was facilitator/co-ordinator of the West Wilts Manic Depressive Fellowship (another user led organisation) and have privately attended conferences on mental health issues in London, Exeter, Taunton and Cardiff. Not bad for someone who was told by an 'expert' that I would 'never be able to work again.' I believe I owe my long period of "wellness" to the especial friendship of Ramo Kabbani of the Prozac Survivors Support Group, the love and support from the many "Prozac" groups to be found on the internet and writers Dr Peter Breggin, Lucy Johnstone, Dr Terry Lynch who had the courage and candour to "whistle blow" on the system, and the many other self help books I have read which have helped me put back together my self-esteem after a long emotionally/psychologically abusive marriage. Knowledge is power. My mental health broke down once - I choose not to stay broken down.



Ballot Form

Please tick the names of the four people you would like to elect to the committee.

Paula Boddington

Terry Burton

Karen Harries

Andrew Isaac

Christopher Keegan

Maddie Leighton

Derek Scott

Janice Simmons

Sarah Venn

Once you have completed your form, you can cut it out and send it to Karishma Jasani at the address on below.

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7. Derek Scott

I have been busy setting up a User Group for Seroxat sufferers since May, and have gathered an extensive amount of information regarding possible side effects, withdrawal symptoms and dependence. There is now a website with correspondence between myself and the Scottish Parliament, Medicines Control Agency, e-mails to Pat Troop, Deputy CMO and Professor Sir Liam Donaldson the Chief Medical Officer for the Government.

The web addresses are <http://www.ds010a5436.pw.p.blueyonder.co.uk/> and <http://arourjs.vahoo.com/groupseroxat/>

Like a lot of you, I have suffered severe side effects, withdrawal symptoms and associated dependence to Seroxat since trying to discontinue the medication at my GP's request last autumn. I suffered a series of adverse reactions to Seroxat, which included high blood pressure, pounding headaches, electric shock like symptoms travelling from my head downwards, which affected my balance and coordination and still does to some degree.

I will let you decide whether or not to vote for me to share a place on the committee, either way I will continue to be a thorn in the side of Glaxo SmithKline and the Medicines Control Agency,

until they admit the extent of the problem, and that they are ultimately to blame.

8. Janice Simmons

I would like to serve on the committee because I want to help other people who are having problems with this drug and other antidepressants. I am not a user of the drug myself but my husband is. I met John (my husband) five years ago, at that point he had been on Seroxat for approx 7 years. He was prescribed antidepressants initially because his marriage was breaking up and his wife was prescribed Prozac. Unfortunately his wife

committed suicide a few weeks later in August 1991 whilst on Prozac. John was then changed to Seroxat. When I met John I was amazed that he was still on antidepressants 7 years later and decided to look into it. Therefore since 1997 I have devoted all my time to researching antidepressants, especially Seroxat.

We have been to numerous GP's/psychiatrists/psychologists/nutritionists/allergy testers, private and NHS. We have spent hundreds of pounds doing this. I have collected every available report on the Internet since 1997/8 regarding antidepressants and have piles of paperwork. I have been to 5 solicitors prior to Hugh James without success. I have also been to see 3 MP's. After 5 years, I think I have quite good knowledge regarding Seroxat and antidepressants in general and have investigated almost every avenue. I also think I could be helpful in supporting the partners of users as we suffer greatly whilst supporting the user. Antidepressants can produce awful side effects/withdrawal symptoms which can seriously affect relationships. Believe me I know!

I was a secretary for 25 years so would be willing to help in that respect if needed. I have my own office at home with computer, printer, fax and scanner. I am also able to transcribe audio tapes and have a typing speed of 80-100 wpm.

John and I were on Radio 4 last year with Charles Medawar and we were on Breakfast TV and the News on 13th June 2002.

It would really mean a lot to me to be elected for the committee because I have put so much time and effort into this subject already and am willing to put in a lot more to help others.

9. Sarah Venn

Research Assistant to the Right Honourable Lord Justice Carnwath CVO Law Commission.

I would like to serve on the Seroxat Users Group Committee to help develop support for users and to raise public awareness of the problems caused by the discontinuation of Seroxat.

I have been taking Seroxat for the past five years. I have tried to withdraw from Seroxat twice in this period, with no success. I am now taking a career break for a year to withdraw from Seroxat and will be following Dr Healy's plan.

I think it is important that the group looks beyond the potential litigation against Glaxo and fulfils a much needed educational and support role, providing physicians and their patients with the information needed to make informed decisions about the prescription of Seroxat and providing support to patients and those that live with and care for them. I also hope to be able to share positive experiences of withdrawal from Seroxat following Dr Healy's plan.

I am twenty-five years old and having spent two years working under a Court of Appeal Judge for the Government in law reform at the Law Commission, I have just qualified as a barrister. I have valuable skills and experience to offer the Seroxat Users Group Committee, which I will be able to dedicate solely to the group next year. My professional training has focused on communication skills, the effective presentation of information and persuasive argument. In my employment I have co-ordinated focus groups, worked with Government departments and written consultation papers and reports for law reform.

Letter to MP

Please insert name and address of your MP here

Dear Mr/Mrs

Re: Seroxat

I am a user of Seroxat, an anti depressant medication manufactured by Glaxo Smith Kline. Seroxat is a member of the category of drugs known as SSRI's (Selective Serotonin Re-Uptake Inhibitor). Seroxat is licensed for the treatment of symptoms of depressive illness of all types.

GSK make a point of saying in the Patient Information Leaflet that this drug is not addictive. I have suffered several side effects from using this drug including difficulties of coming off it yet the World Health Organisation lists Seroxat as being at the top of its league table of drugs that have difficulties of withdrawal.

These side effects are well known to the Government's Medicine Controls Agency but GSK are refusing to acknowledge the problems caused by this drug.

I would therefore like you as a matter of urgency to call upon the Department of Health to look into the number of reports of problems with this drug.

Yours sincerely