CV of Millie Kieve, relating to role as Founder and Chair of APRIL
(Adverse Psychiatric Reactions Information Link) May 2013

A: ROLE

I have studied harm caused by adverse side effects of everyday medicines and anaesthetics, focusing on the psychological changes that lead to depression, anxiety, homicide and suicide. I represent the voices of thousands who have suffered harm, for those who are addicted to prescribed medicines and of bereaved families who have contacted me. I link people with problems to those who may help them. (See attached PC's statement re anti-smoking drug/alcohol interaction.)

B: ACTIONS

I have been invited to present information about patient experiences to health professionals in conferences, meetings and for official inquiries by the following organisations and research projects:

- **The Nursing and Midwifery Council (NMC)** I was invited to participate in workshops to develop improvement of education for midwives.
- **Government Health Select Committee** – I submitted evidence about involuntary tranquilliser addiction & for the Inquiry in to the influences of the pharmaceutical industry (evidence submitted in on the government web site).
- **British Medical Association (BMA)** I was invited to discuss patient information data provision and general matters regarding patient safety (minutes of meeting can be provided).
- **Medicines Healthcare Products Regulatory Agency (MHRA)** – I was consulted for opinion about patient information leaflets design and content, to include clarity of Seroxat/Paxil/ paroxetine suicide risk warning.
- I was invited to do presentation to directors of MHRA to support onset of patients being allowed to report adverse drug reactions (ADRs). I had previously campaigned for health professionals, other than doctors to use the Yellow Card system of reporting ADRs.
- **MHRA** I campaigned in person and by email and letter about the need to raise awareness of extent of Dianette induced depression. The MHRA eventually reviewed more than 100 emails sent to APRIL. Many women complained they were prescribed antidepressants for Dianette induced depression. An article in The Guardian is self explanatory : "Pill under review over link to depression": http://www.guardian.co.uk/society/2006/may/08/health.medicineandhealth
- **European Medicines Agency (EMA)** - Review of patient information for Seroxat (paroxetine) Joined Seroxat User Group to advise on additional suicide warning for patient information leaflets.
- **National Patient Safety Agency (NPSA)** –I was invited in person, to submit evidence about anaesthetics & corticosteroids ADRs.
- **National Clinical Assessment Service (NCAS)** – I was invited to attend a two day workshop for patient groups. We submitted ideas about identifying failings in healthcare and developing further education for healthcare professionals falling short of required standards.
- **Suicide Prevention Strategy for England (NHS)** – I submitted evidence and had personal meetings with Prof Louis Appleby to rectify the lack of information in the Strategy about medication induced suicide (iatrogenic effects).

- **Suicide Prevention Strategy for Westminster, Kensington/Chelsea & Hammersmith & Fulham** (Inner N W London Primary Care Trust). I participated in working group to reduce suicides in the boroughs.
- **British Transport Police Public Protection Unit** – I was invited to speak to the unit about medication ADRs causing self harm, violent behaviour and suicides. This has influenced their attitude to people they come across who appear to be vulnerable to harm. Also collection and submission of data about medication will now be included in data for submission to coroners.
- **Ministry of Justice for Coroners' Reviews** –I was consulted regarding suggested verdicts in cases involving ADRs and related information to improve the service for the public.
- **European Medicines Agency (EMA)** - Review of Diane 35 (Dianette) following ban in France due to thrombosis deaths – I responded to EMA consultation about the warnings/adverse effects of Dianette (cyproterone acetate/ethinylestradiol)
- **NHS North West** – Non medical Prescribers Conference – invited to annual meeting to give keynote presentation of patients' experiences of ADRs. Asked and gave permission for our videos of experiences of ADRs and suicide to be linked to universities in Manchester and Edinburgh.
- **Prescribing & Research in Medicines Management (PRIMM)** Conference "Adverse Drug Reactions: is the patient voice loud enough?" – I organised and presented the patient experience section of the conference and helped with publicity.
- **British Computer Society Annual Conference** - I gave presentation as keynote speaker.
- **National Institute of Clinical Excellence (NICE)** - I have been a stakeholder in development of guidelines for depression but was very disappointed when they refused to include possible ADR from existing treatment as a cause of depression. I have met and obtained concession that NICE could put on their website withdrawal protocols for reducing addictive benzodiazepines and SSRI antidepressants. In spite of support from MP Jim Dobbin and letters from APRIL to Meindhert Boyson at NICE, there has been a negative result so far. I met Mr Boyson in Holland while attending the "Selling Sickness" World Health Organisation supported conference.
- **Evaluation of Patient Reporting of ADRs using the Yellow Card scheme** - **Appointment as Chair of Advisory Group to Evaluation of Patient Reporting**
  I was invited by Professor Anthony Avery to form a committee and to chair the Advisory Group to the Evaluation of patient reporting. Anthony Avery is Professor of GP practice at Nottingham University. This entailed overseeing the work of scientists in Universities of Nottingham, Aberdeen, John Moore's Liverpool and the Drug Safety Research Unit.
  The report found patients had identified signals of ADRs missing from Healthcare Professional reporting. The report published by Health Technology Assessment May 2011: http://www.hta.ac.uk/project/1628.asp

Investigation of failure of Yellow Card ADR Reporting System in the 90's

The MHRA estimates less than 10% of serious ADRs are reported.

I campaigned for patients to be allowed to report ADRs to the regulator, following research into the system of pharmacovigilance in the UK. I found serious failings. Pharmaceutical companies are legally obliged to report all ADRs they receive information about.

I followed the trail of a letter sent by consultant gastroenterologist, Dr Martin Sarner, in 1995 reporting my daughter's psychotic breakdown linked to her taking sulphasalazine.

The manufacturer, Pharmacia received the letter from Dr Sarner but did not forward the information to the medicines regulator as they were required by law to do.

I found too that pharmaceutical companies are not required to disclose data about serious ADRs occurring in clinical trials. These events include suicides and are undisclosed to the regulator under the guise of "confidentiality". I made further inquiries and was informed by a pharmacist that their reports were destroyed. Reporting ADRs to the MHRA was limited to doctors.

I have been commissioned to write articles including:
New Scientist : Why we must listen to patients - Falling on Deaf Ears (Comment)
Quality in Primary Care: Adverse drug reactions (ADRs): a patient perspective on assessment and prevention in primary care
The Guardian : "She told me she had lost her personality"
http://www.guardian.co.uk/society/2004/aug/17/health.lifeandhealth
Nurse Prescriber: http://www.internurse.com/cgi-bin/go.pl/library/article.cgi?uid=17230;article=NP_2_6_238;format=pdf

Research for documentaries and current affairs programmes:
I was featured in French Arté current affairs programme about patient reporting following Mediator drug scandal.
I did research for programmes on Channel 4 and BBC about ADRs
I was interviewed on Internet Health Radio and Essex Radio Dave Monk show

Medical Education – action towards improvement
I have influenced the Education Committee of the General Medical Council (GMC) about the need for medical students to learn about "side-effects". This term was added to the GMC guidelines 'Tomorrow's Doctors' in 2001.
Professor David Hatch thanked me for drawing the attention of the GMC to the omission from their guidelines on medical education.
I continue to press for the re-introduction of clinical pharmacology and therapeutics to the curriculum of medical schools in the UK. Since the subject was removed from the guidelines in 1993, many pharmacology departments have closed. I support the work of Professor Simon Maxwell in this area, as he supports my efforts. Professor Maxwell has suggested and agreed to support presentations in Science festivals – this has yet to be instigated.

I organised three conferences in London in 2001, 2004 and 2008.
Leading experts in the field of ADRs, anaesthetics, pharmacogenetics and pharmacology came from UK, Canada and the USA to support my efforts. The experts received no money for sharing their expertise and concerns and have continued to support the work of APRIL with their advice and by sharing their expertise. Link to details of participants in the conferences: http://www.april.org.uk/main/index.php?uid=225&
Reviews of APRIL conferences:
http://www.haringey.gov.uk/winter_spring2009.pdf
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC527726/
http://www.bmj.com/content/329/7475/1124.3

APRIL's web site www.april.org.uk is found to be of value for many people. We include many links to: scientific papers: data and articles in journals : to BBC programmes.
Sharing the expertise of professors, doctors, psychiatrists and academics.
We provide free access to talks from our conferences and patient's experiences. These are used by universities for educational purposes and by the public to obtain information from experts. Some videos may be accessed via our web site, with access to more or our videos at this link:

http://vimeo.com/user1816628/videos

C: BACKGROUND

I founded the charity APRIL (Adverse Psychiatric Reactions Information Link) in 1998, following the death of my 30-year old daughter, Karen.

I was concerned to find out exactly what had happened to Karen. I found that she had been both mis-diagnosed and mis-prescribed, with drugs she could not tolerate.

My early research at the British Library Medical Department, led me to suspect that Karen's experience was not in isolation but represented the tip of a very large iceberg of misinformation and lack of awareness among the medical profession and the public.

Professor Simon Maxwell's survey, which found medical students' education in the area of medicines was inadequate to enable safe prescribing, confirmed my concerns.

I was granted a Millennium Award for research into Suicide Prevention. This enabled me to learn from Professors of Suicideology and expert lawyers in the USA. I learned the distinguishing features of planned suicides and sudden onset to suicide or suicidal ideation triggered by medication adverse effects.

At the same time as finding ways to identify suicides linked to ADRs, I set out to discover why a state of affairs existed in the UK where doctors were not educated to recognise early signs of intolerance to medication. Drugs to treat the symptoms are often prescribed, instead of stopping treatment or reducing dosage, to ascertain is ADR is the cause of symptoms.

I learned from Professor Pirmohamed's study of admissions to A & E in two Liverpool hospitals that 1 in 16 admissions were due to ADRs - costing the NHS £500 million a year.

Recent analysis of hospital admissions show a seriously worrying increase in admissions to A & E due to ADRs which has increased by 76.8% which is more than any other cause. Deaths have increased by 10%.

The work of APRIL is important and I will do my best to fulfil Aims and Objective to:

Promote the preservation of mental health by relieving and protecting persons who may at risk from adverse psychiatric reactions to drugs related to medical treatment.

APRIL
Adverse Psychiatric Reactions Information Link

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