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Professor Guido Rasi
Executive Director
European Medicines Agency
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Dear Professor Rasi

We have participated in clinical trials in the last 30 years.

Some of us are healthy individuals and some of us have medical conditions. Some of us probably received the treatment under investigation in the trial and some of us were given the control treatment or placebo.

Whatever the case, we all agreed to participate in the trials in the belief that we were helping to improve knowledge and treatments. We now understand that many participants in trials have been misled. Current evidence shows that, overall, about half of all clinical trials have not been published and that this proportion has seen only a small improvement over the past few years. Furthermore, both companies and independent researchers can withhold information about clinical trials from doctors and researchers even when asked for it.

This means that the findings generated from our participation and that of thousands of others in the trials may not be available to the doctors, researchers and regulators who work on particular diseases or make decisions about their treatments. It also means that some of the trials could be repeated in the future, when they do not need to be.

This is dangerous and expensive and it holds back good medicine. It is also a betrayal of our trust in clinical trial regulation, and the trust of the families of those patients who volunteer for trials having had a terminal diagnosis.

The Clinical Trials Regulation is currently being debated in the European Parliament. We want you to put in place measures to ensure that the protocols for all clinical trials from now on - and all clinical trials since the 1980s – are posted on a public register; and that the summary results, the “primary and secondary outcomes” measured in all these trials and the Clinical Study Reports are published.

Signed

Name	Description of trial	Date of trial
Iain Chalmers	Oxford Vaccine Group's test of a new pneumococcal vaccine	c 2008-2009
Richard Stephens	Trial of drug combinations in Lymphoma	1998
	Trial of PET scans as prognostic indicators in Lymphoma	1999
	Trial of blood anti-clotting agents in heart patients	2007
Lauren Gore	Test of potential new eczema treatment on healthy volunteers.	August 2012
Richard Smith	The trial was a double blind randomised controlled crossover trial to see if the polypill would reduce blood pressure and blood lipids. It lasted about six months. The polypill did reduce blood pressure and blood lipids.	2011
Sarah Stevens	Undertaken at St Barts Hospital for GW Pharma to assess effectiveness of Sativex for muscle spasms (trial was double blind). Condition: multiple sclerosis.	c 2006
Dominic Haigh	TREK Study Description: Participants from several different European countries were given either a patch immunising against traveller's diarrhoea or an inert placebo and dispatched to countries where they might become infected with the disease. I went to stay in Guatemala City for a week.	January 2010
Nancy Kane	Beta SNP trial; study examining whether differences in genes affect how vitamin A is used by the body.	October 2012
Ralph Cantellow	The PACE trial was a randomised controlled trial of treatments for chronic fatigue syndrome also known as myalgic encephalomyelitis or myalgic encephalopathy. The trial, which involved 640 patients, was conducted in six hospitals in England and Scotland and compared the safety and effectiveness of four treatments: Specialist medical care (SMC) alone, and SMC plus one of the following therapies: adaptive pacing therapy cognitive behaviour therapy, and graded exercise therapy.	March 2003- January 2010

Mei Lee	Phase 3 trials of Novartis's vaccine against neisseria meningitides B	2009-2010
Sam L	It was an antidepressant study looking at drugs affecting glutamate (ketamine and a new drug AZD6765)	February-March 2010
Charis Croft	The trial is between subcutaneous injections and sublingual tablets as a mechanism for administering immunotherapy to relieve hay fever arising from grass pollen.	September 2012- ongoing
Joanne Evans	Trialling BMN110 enzyme replacement therapy for Morquio's Syndrome (Mucopolysaccharide IVA)	August 2011-January 2012
Phil Booth	Trials of anti-epilepsy and pre-diabetes treatments	1988-1989
Rachel Pearce	My trial is called SOFT (Suppression of Ovarian Function Trial) and is a 3-arm trial testing the benefits and disadvantages of: Tamoxifen, Tamoxifen + ovarian function suppression, Exemestane + ovarian function suppression in premenopausal women with hormone receptor positive breast cancer.	2003- 2011
Thomas Edward Hills	Single dose of a generic formulation of bicalutamide (anti-androgen for prostate Ca) – pharmacokinetic study.	c June 2005
Helen Ap-Rhisiart, on behalf of my daughter, now aged twelve	Oxford Vaccine Group (Univ Oxford) meningitis C/pneumonia combination vaccine study.	2000-2003
Brian Sewell	Trial for a drug to control high blood pressure	1992
Caroline Richmond	Vitamin C and the common cold MRSA in denture wearers COPD	c 1984 c 2005 2013
Ryan Geleit	First into human trial to assess a new compound for the treatment of Acute Lung Injury and Acute Respiratory Distress Syndrome	February 2012
Richard Desmond	Concorde trial into the efficacy of treating infection with HIV	1989-1991
A'Llyn Ettien	Yearlong trial of drug combination to prevent bone thinning	2005-2006

	3-month trial of birth control patch comparing usability to ring	Summer 2007
James Warwick	Final phase RCT for a new meningitis vaccine developed by Novartis	October 2010-2011
Kevin Nickells	Clinical trial into the affects of alcohol on nicotine dependency	August 2010
Michael Wing	The trial was based at St Georges Hospital, Tooting, London. I underwent 12 hours of an intravenous infusion of deuterium enriched water preceded and followed by a blood test. I also had a repeat blood test 2 weeks later. The study was to identify the maturation rate of lymphocytes.	2001-2002
Khairil Hodgson	FluCamp a phase 2a, randomized, double blind, placebo controlled study to Investigate the effects of VX 787 administered to adult volunteers experimentally inoculated with live influenza virus	August 2012
Dr Aaron Dale	Addenbrookes Hospital for GSK for a painkiller FluCamp to test an influenza vaccine	2007 December 2012
Kathryn M Burke	The trial was Fingolimod (Gilenya) phase III. The trial was to test safety and efficacy.	2007
Harry Purser	Trial for a peripheral system analgesic.	April 2010
Gillian Lang	During pregnancy my blood pressure was monitored and samples of placenta taken following the birth	March - November 2002
Hester Tidcombe on behalf of my son	Post-authorisation safety study of GSK's pandemic flu vaccine in the UK	November 2009
Chris Murphy	For diabetes	Autumn 2004
Hilary Foote	The effects of natural bran food supplement on irritable bowel syndrome	c 1994
Michael James Fox	The trial was for the norovirus	Summer 2009
Darran Shepherd	Malaria vaccination trial	January 2010

Christopher John Parlett	I participated in three medical trials at the Department of Respiratory Medicine and Allergy, King's College, London All trials were said to be for the testing of alternatives to current corticosteroid treatments for asthma.	2001 -2003
Denise Syndercombe Court	Tamoxifen +/- (Zoladex) randomised- given for 2 years duration. Given for stage I/II breast cancer in premenopausal women (including those with positive nodes)	1994-1995
Linton Lahoud	Effects of light on sleep	c 2011
Dr Gemma Bashevoy	A trial for a malaria vaccine	January 2011-September 2012
Dr Maxim Bashevoy	A clinical trial for hay fever using a drug called rPhleum (immunotherapy)	c 2009
Nicola Branch	Trialling a gel to help reduce the spread of HIV amongst heterosexuals in Africa	2004- 2005
Leslie Rose	Phase I study of effects of a beta-blocker on muscle blood flow. Injection of a radio-label into anterior tibialis muscle, followed by treadmill exercise testing.	1980
	Acupuncture in neck pain. The purpose of the study was to evaluate electro-acupuncture in comparison with normal acupuncture and placebo electro-acupuncture.	2004
Adam Barnett		
Katherine Hunter		
Kieran Crean		
Matthew Valentine, MD	Roche trial of Oseltamivir (Tamiflu). Recruited with active flu-like illness as a medical student at Oregon Health and Sciences University in Portland, Oregon, USA for randomized controlled trial of Oseltamivir	Autumn 1998
Amanda Burls	The intervention was probiotic yoghurt versus non-probiotic yoghurt for IBS	2005

Martin Law	Get Moving run by the MRC epidemiology Unit	October 2012- February 2013
Carmen Major		
Cynthia Dumas	Phase III randomized study of treatment based on response to induction chemotherapy in patients with higher risk childhood acute lymphocytic leukaemia	April 2001- July 2003
Amanda Kerr on behalf of my son	Infant vaccine trial	2008-2009
Sean Murphy	Interaction of an antihistamine and an anti-fungal drug	1993
	Interaction of a 5HT1A receptor agonist and alcohol.	1993
Veronica Klein Michelle Fraser		