**CONTACT DETAILS**

Email: alastair@alastairkent.com

www.alastairkent.com

**EMPLOYMENT**

2017 - April 2018 Ambassador, Genetic Alliance UK

1993 - 2017 Executive Director, Genetic Alliance UK

1989 - 1993 Executive Director, Action for Blind People

1986 - 1989 Director of Education, Employment and Residential Services, Royal National Institute for Deaf People

1982 - 1986 Principal (Banstead Place), Queen Elizabeth's Foundation for the Disabled

1981 - 1982 County Careers Officer (Special Needs), North Yorkshire County Council

1977 - 1981 Specialist Careers Officer, Cambridge County Council

1973 - 1977 Careers Officer, Norfolk County Council

**GOVERNMENT APPOINTMENTS**

2002 - 2011 Human Genetics Commission Member (Department of Health)

2013 - 2016 Department of Health Rare Disease Stakeholder Forum (Chair from 2014)

2015 - present: Synthetic Biology Leadership Council, Deparment of Business, Enterprise and Industrial Strategy (BEIS) Member , Council and Governance Sub Group

2016 - present: Co-chair UK Rare Disease Policy Board (Department of Health and devolved administrations

**OTHER APPOINTMENTS**

1993 - 1994 Worcester Polytechnic Institute (USA), Associate (Visiting) Professor

2002 - 2006 Non Executive Director, Cambridge City NHS Primary Care Trust

1996 - 2006 Justice of the Peace, Cambridge PSD

2016 - present: Science and Ethics Advisory Committee, Roche PLC

2016 - present: Ethics Committee, Illumina PLC

2018 - present: Access Committee, Raremark

**COMMITTEES**

2008 - 2011 Committee for Advanced Therapies, EMA

2007 - 2013 “1000 Genomes” International Project Ethics Committee

2006 - 2011 “Clinigene” NoE International Advisory Board Member

2004 - present: Public Population Projects in Genetics (P3G) Ethics Committee

2004 - 2005 International HapMap Project Ethics Committee

2003 - 2004 EU STRATA Group on Genetic Testing

2003 - 2018 UK Genetics Testing Network Steering Committee (NHS England)

2002 - 2012 Dept. of Health Genetics Commissioning Advisory Group (GenCAG)

2000 - 2006 Patient Representative Orphan Medicinal Products Committee, EMEA

1998 - 2000 Anglia and Oxford Public Health Genetics Unit Steering Committee

1997 - 2017 Royal College of Physicians (Now Joint Committee of the RCP, RCPath and British Society for Human Genetics) Clinical Genetics Committee.

1997 - 2000 Standing Advisory Group on Consumer Involvement in the NHS R & D Programme (now known as “INVOLVE”).

1996 - 2013 European Federation of Biotechnology Task Group on the Public Perceptions of Biotechnology

1996 - present: Association of British Insurers Genetics Advisory Committee

1995 - 1998 BMA Ethics and Genetics Working Party

1993 - present: European Alliance of Genetic Support Groups (President 1995 - present)

2004 - 2008 EU Rare Disease Task Force (DG SANCO)

2008 - 2012 EU Committee of Experts on Rare Diseases (DG SANCO)

2012 - 2017 EU Expert Group on Rare Diseases (DG SANCO)

2009 - 2018 Founder and Chair of Rare Disease UK

2013 - Scottish Medicines Consortium Task & Finish Group on improving access to medicines for patients with rare diseases.

2013 - present: Genomics England Ethics Advisory Committee

2013 - present: NHS England Rare Diseases Advisory Group

**OTHER ACTIVITIES AND AWARDS**

I have also spoken at and/or chaired a large number of national and international conferences and seminars, written for popular and specialist papers, magazines and academic journals and appeared frequently on TV and radio.

I was awarded the OBE for services to Healthcare in 2011.

I was elected a Fellow of the Royal Society of Arts in 2017 for my contribution to supporting patients and families with genetic diseases.