

## The QALY project

108 UK organisations that take an active interest in the quality of life of patients, people with a disability, carers, and citizens

### A

- ▶ Action on Pain  
<http://www.action-on-pain.co.uk>
- ▶ ADDER (Action for Dystonia, Diagnosis, Education and Research)  
<http://www.dystonia.co.uk>
- ▶ Advocacy Alliance  
<http://www.advocacyalliance.co.uk>
- ▶ Age Concern Kensington and Chelsea  
<http://www.ackc.org.uk>
- ▶ Age Concern Swansea  
<http://www.ageconcernswansea.org.uk>
- ▶ Anaphylaxis Campaign, The  
<http://www.anaphylaxis.org.uk>
- ▶ Androgen Insensitivity Syndrome Support Group (AISSG)  
<http://www.aissg.org>
- ▶ Angioma Alliance UK  
<http://www.angiomaalliance.org.uk>
- ▶ ALD (Adrenoleukodystrophy) Life  
<http://www.aldlife.org>
- ▶ Anxiety Care  
<http://www.anxietycare.org.uk>
- ▶ Arrhythmia Alliance (AA)  
<http://www.aral.org.uk>
- ▶ Asperger East Anglia  
<http://www.asperger.org.uk>

### B

- ▶ BackCare [the National Back Pain Association]  
<http://www.backpain.org>
- ▶ Back-Up Trust, The  
<http://www.backuptrust.org.uk>
- ▶ Birmingham Adult Dyslexic Group (BADG)  
<http://www.badg.org>
- ▶ Bosom Friends: Oxford
- ▶ Bradford and District Autistic Support Group (BADASG)  
<http://www.badasg.ik.com>
- ▶ Brain Tumour UK  
<http://www.braintumouruk.org.uk>
- ▶ British Liver Trust  
<http://www.britishlivertrust.org.uk>
- ▶ British Thyroid Foundation (BTF)  
<http://www.btf-thyroid.org>

### C

- ▶ Cancer Counselling Trust, The  
<http://www.cctrust.org.uk>
- ▶ Carers Advice and Resource Establishment (CARES): Sandwell
- ▶ Changes (12 Steps to Mental Health)

- <http://www.changes.org.uk>
- ▶ **Chronic Granulomatous Disorder (CGD) Research Trust**  
<http://www.cgd.org.uk>
- ▶ **Citizen Advocacy Trust Gloucestershire: Forest of Dean**
- ▶ **CLASP: the Carers Centre**  
<http://www.claspthecarerscentre.org.uk>
- ▶ **Connect: the Communication Disability Network**  
<http://www.ukconnect.org>
- ▶ **Continence Foundation**  
<http://www.continence-foundation.org.uk>
- ▶ **Crossroads Caring for Carers: Cumbria**
- ▶ **Crossroads in the Vale (EMI) Ltd**

## D

- ▶ **DANDA (Developmental Adult Neuro-Diversity Association)**  
<http://www.danda.org.uk>
- ▶ **Deafness Research UK**  
<http://www.deafnessresearch.org.uk>
- ▶ **Diabetes UK**  
<http://www.diabetes.org.uk>
- ▶ **Diabetes UK: St Albans and District Voluntary Diabetes Support Group**  
<http://www.diabetessupportstalbans.org.uk>
- ▶ **Dialability**  
<http://www.dialability.org.uk>
- ▶ **Disability Cornwall**  
<http://www.disabilitycornwall.org.uk>
- ▶ **Do You Panic**  
<http://www.doyoupanic.co.uk>
- ▶ **Dyspraxia Foundation: Bristol and South Gloucestershire Support Group**  
[http://www.dyspraxiafoundation.org.uk/info/show\\_local.php?id=7](http://www.dyspraxiafoundation.org.uk/info/show_local.php?id=7)
- ▶ **Dystonia Society, The**  
<http://www.dystonia.org.uk>

## E

- ▶ **East Lancs ME/CFS Support Group**  
<http://www.eastlancsme.org.uk>
- ▶ **Eating Disorders Association (EDA)/ Beat Eating Disorders (BEAT)**  
<http://www.edauk.com> / <http://www.b-eat.co.uk>
- ▶ **Epilepsy Action [British Epilepsy Association]**  
<http://www.epilepsy.org.uk>
- ▶ **Epilepsy Action: Birmingham**
- ▶ **Essex Coalition of Disabled People (ECDP)**  
<http://www.ecdp.org.uk>
- ▶ **Eurochild**  
<http://www.Eurochild.org>
- ▶ **European Network of (ex-) Users and Survivors of Psychiatry (ENUSP)**  
<http://www.enusp.org>

## F

- ▶ **Fibromyalgia Association UK (FMA UK)**  
<http://www.fmauk.org>
- ▶ **Fibromyalgia Support Group for Surrey and Sussex (FMS SaS)**

<http://www.fibromyalgia-south.com>

▶ **Freshwinds**

<http://www.freshwinds.org.uk>

## G

## H

▶ **Hammersmith and Fulham Carers Centre**

<http://www.carers.org/hf>

▶ **Hart Voluntary Action (HVA)**

<http://www.hartvolaction.org.uk>

▶ **Having A Voice**

<http://www.havingavoice.org>

▶ **Heart Care Partnership UK (HCPUK)**

[http://www.bcs.com/pages/aff\\_detail.asp?AfID=12](http://www.bcs.com/pages/aff_detail.asp?AfID=12)

▶ **Help the Hospices User Group**

<http://www.helpthehospices.org.uk/usersvoices/index.asp?submenu=5>

▶ **Herpes Viruses Association (HVA) and Shingles Support Society**

<http://www.herpes.org.uk>

▶ **Hypoparathyroidism (HPTH) UK**

<http://www.hpth.org.uk>

## I

▶ **International Community of Women Living with HIV/AIDS (ICW)**

<http://www.icw.org>

▶ **International Glaucoma Association (IGA)**

<http://www.glaucoma-association.com>

▶ **Invest In ME (IIME)**

<http://www.investinme.org>

▶ **Islington Carers Forum**

<http://www.carers.org/local/london/islington>

## J

## K

## L

▶ **Let's Face It**

<http://www.lets-face-it.org.uk>

▶ **LIVERNORTH**

<http://www.livernorth.org.uk>

▶ **London RSI Support Group**

<http://www.londonrsisupportgroup.org.uk>

▶ **LTCA (Long-term Conditions Alliance, The)**

<http://www.ltca.org.uk>

## M

- ▶ **Manchester People First**  
<http://www.manpf.org>
- ▶ **Mencap (Royal Society for Mentally Handicapped Children and Adults)**  
<http://www.mencap.org.uk>
- ▶ **Mencap: St Albans**
- ▶ **Mencap: Torbay**
- ▶ **Mind (National Association for Mental Health): Derwentside**  
<http://www.mind.org.uk/Mind+in+your+area/Regions/north/Derwentside+Mind.htm>
- ▶ **MK Kids with Diabetes**  
<http://www.mkkidswithdiabetes.org>
- ▶ **Moor Allerton Elderly Care (MAECare)**  
<http://www.maecare.org.uk>
- ▶ **Motor Neurone Disease (MND) Association**  
<http://www.mndassociation.org>
- ▶ **Multiple Sclerosis (MS) Society: Blackpool, Fylde & Wyre**  
[http://www.mssociety.org.uk/branches/lancs\\_and\\_s\\_cumbria/blackpool/index.html](http://www.mssociety.org.uk/branches/lancs_and_s_cumbria/blackpool/index.html)
- ▶ **Multiple Sclerosis (MS) Society: Islington**  
<http://www.mssociety.org.uk/regions/london/branches/islington.html>

## N

- ▶ **National Autistic Society (NAS), The**  
<http://www.nas.org.uk>
- ▶ **National Autistic Society (NAS): North Yorkshire Central**  
<http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=914&a=9859>
- ▶ **Network MESH (West London)**  
<http://www.networkmesh-westlondon-me.org>

## O

- ▶ **Obsessive-Compulsive Disorder (OCD) Centre**  
<http://www.ocdcentre.com>

## P

- ▶ **Parkinsons Disease Society (PDS): Mid Cornwall**  
<http://www.parkinsons.org.uk/templates/branchinternal.asp?NodeID=91930>
- ▶ **Parkinson's Disease Society: Sutton, Kingston, and Epsom Working Age Group (WAG)**  
<http://www.parkinsons.org.uk/Templates/BranchInternal.asp?NodeID=99068>
- ▶ **Patient Information Forum (PiF)**  
<http://www.pifonline.org.uk>
- ▶ **Patient and Public (PPI) Involvement Forum Kensington and Chelsea (Threshold Nevern Residents Group)**  
<http://www.cppih.org/forum/kensingtonandchelsea0330.html>
- ▶ **PCaSO Prostate Cancer Network**  
<http://www.pcaso.com>
- ▶ **Pelvic Partnership, The**  
<http://www.pelvicpartnership.org.uk>
- ▶ **Pituitary Foundation, The**  
<http://www.pituitary.org.uk>
- ▶ **Prader-Willi Syndrome Association (PWSA) UK**  
<http://www.pwsa.co.uk>
- ▶ **Primary Ciliary Dyskinesia (PCD) Family Support Group**  
<http://www.pcdsupport.org.uk>
- ▶ **Progressive Supranuclear Palsy [PSP-Europe] Association, The**

<http://www.pspeur.org>

- ▶ **Prostate Cancer Support Yahoo egroup**  
<http://health.groups.yahoo.com/group/ProstateCancerSupport>
- ▶ **Prostate Research Campaign UK**  
<http://www.prostate-research.org.uk>

## Q

- ▶ **Queen Elizabeth's Foundation**  
<http://www.qef.org.uk>

## R

- ▶ **Redbridge Disability Association (ReDa)**  
<http://www.redbridge.gov.uk/services/index.cfm/217/show>
- ▶ **Rethink**  
<http://www.rethink.org>
- ▶ **RNID (Royal National Institute for Deaf and Hard of Hearing People, The)**  
<http://www.rnid.org.uk>
- ▶ **Risk Placement Services (RPS) Ltd**  
<http://www.riskplacement.com>
- ▶ **Ryedale In-Touch Group**

## S

- ▶ **Sarcoma UK**  
<http://www.sarcoma-uk.org>
- ▶ **Scoliosis Association UK (SAUK)**  
<http://www.sauk.org.uk>
- ▶ **Southwark Carers**  
<http://www.southwarkcarers.org.uk>
- ▶ **Stockton Shopmobility Ltd**  
<http://www.stocktonshopmobility.com>
- ▶ **Stroke Association, The**  
<http://www.stroke.org.uk>

## T

- ▶ **Trafford Asian Women's Network**

## U

- ▶ **UK National Work-Stress Network, The**  
<http://www.workstress.net>

## V

- ▶ **VODA (Voluntary Organisations Development Agency): North Tyneside**  
<http://www.voda.org.uk/history.html>
- ▶ **Voluntary Action Westminster (VAW)**  
<http://www.vawcvs.org>

## W

- ▶ **WAMES (Welsh Association of ME & CFS Support)**  
<http://www.wames.org.uk>
- ▶ **West Riding Blind Association (WRBA)**  
<http://www.wrba.org.uk>
- ▶ **Wolverhampton Rheumatology Support Group (WRSB)**  
<http://www.wrsb.org.uk>

Source: QALYity Project survey of UK patient groups, December 2006-January 2007