WHAT DOES EQUITY MEAN TO YOU?

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Alexion Pharmaceuticals, Amgen, Amicus Therapeutics, BioCryst, Biogen, Chiesi, Illumina, Ipsen, Jazz Pharmaceuticals, Kyowa Kirin, Novartis Pharmaceuticals, Pharming, PTC Therapeutics, Sanofi, Takeda, Ultragenyx Pharmaceutical, Vertex Pharmaceuticals.

GENETIC ALLIANCE UK

"SUPPORTING INTERNATIONAL COLLABORATION TO SHARE BEST PRACTICE and resources to increase QUALITY OF LIFE AND LIFE EXPECTANCY."

"BEING SEEN AS A PERSON NOT A PROBLEM."

"GREATER AWARENESS among healthcare professionals so that rare diseases are RECOGNISED rather than overlooked."

"Help accessing Personal Indepedence Payments."

"ACCOMODATIONS so that I can be INVOLVED in the local community e.g. accessible business."

"INCLUSION"

"Working WITH the patient/carer as part of the team, keeping them INFORMED and EDUCATED."

"FULL ACCESS to TESTING, SUPPORT, TREATMENT + RESEARCH for GENETIC CONDITIONS."

"THOROUGH TESTING FOR ALL EVENTUALITIES"

"We see how RARITY can translate into INVISIBLE"

Delayed diagnoses, fragmented care, families carrying an enormous emotional and practical burden with little support."

"EQUITY is not as simple as being "REPRESENTED" or having a PATIENT VOICE at the table."

EQUITY means creating GENUINE opportunities for families, children and young adults to BE PART OF THE WORK ITSELF lead research, advocacy, shape, direction, co-design resources and direct us to WHAT MATTERS MOST."

"EQUAL access to CARE AT HOME SUCH as OPAT"

"SOMEONE KNOWING about my CONDITION."

"Rather than seeing several professionals LOOKING AT ONE SYMPTOM at a time Speak to ONE person who can LINK THEM."

"...FINANCIAL SECURITY

EMPLOYMENT

"Parents of children with rare diseases often have to drop out of employment leading to financial challenges...

...Although they have access to disability allowances these are cut rapidly if the child dies...

DEBT

GRIEF

...this results in parents with a loss of money + employment as well as grieving the loss of a child and no easy route back into employment."

"Access to EXPERTISE and RESEARCH OPPORTUNITIES EVEN FOR THE SMALLEST Patient groups."

"...To be HEARD and BELIEVED."

FORMAL DEFINITION: "the quality of being fair and just, especially in a way that takes account of and seeks to address existing inequalities." (Oxford English Dictionary)

VISUAL MINUTES BY ROSE MATHESON @ROSESUSCITATION

"Our whole community can access the same standard of care regardless of: LOCATION, SOCIOECONOMIC BACKGROUND OR ETHNICITY."

"Dedicated NURSING Support"

"...To have our case reviewed at an MDT meeting (and be PRESENT where appropriate."

"...Having a SUPPORT GROUP for ADVICE and INFORMATION."

Access to health + social care without BARRIERS

"Access to an effective TREATMENT."

"...Not having EXCESSIVE DURATIONS OF TIME between appointments."

"COORDINATED COMPASSIONATE CARE THAT DOESN'T DEPEND ON GEOGRAPHY OR PERSONAL ADVOCACY"

"EVERY family having quick receipts of Post Mortem
EVERY family has equal access to cardiac screening + genetic testing
A statuatory obligation to document and report on cases that remain unexplained
EVERY family must be supported
EVERY professional must be trained
in Sudden Unexplained Death in Childhood."

"...Being able to have the CONFIDENCE and ABILITY to do NORMAL things in life:
Get a job, Use public transport."

"HONESTY regarding EXPENSIVE personalised gene therapies that may struggle to ever be made available to the majority who could benefit from them via the NHS."

TREATMENTS

"FASTER, MORE ACCURATE DIAGNOSIS"

"Mental Health at all Stages of the diagnostic process Support and continuing thereafter."

"...Having all her needs catered for at school."

"Being able to TRAVEL UNAIDED Without being frightened of tripping over, being able to read a menu without a magnifying glass."

"EMPLOYABILITY FLEXIBILITY"

Treated the same as any other patient

"BEING INCLUDED Within a Workplace Within the healthcare system."

...Having access to the WIDER MDT."

"We would ALL like access to heathcare professionals that KNOW and UNDERSTAND our conditions. However, rare diseases are RARE by definition and it is very DIFFICULT for medics to be well informed on RARE CONDITIONS. EQUITY looks like sufficient TIME with our Consultants + GPs to discuss an issue... ...them to be RECEPTIVE to the issue and them having time to Research a Solution OR REACH to peers or further research and come back to you. TIME to follow up if solutions resolved an issue or improved quality of life."

"MENTAL HEALTH OR NEURODIVERGENCE NOT TO GET IN THE WAY OF BEING LISTENED TO."

"A dedicated point of contact we are so rare that there is NO 'HOME' for us within the NHS and we have to rely on generalist services e.g GP services, A+E which is not equitable to other conditions that have dedicated specialist services."

"CO-ORDINATING SPECIALIST CARE"

"...that means NO ONE is DISADVANTAGED Simply because their condition is UNFAMILIAR, COMPLEX or only affects a handful of people worldwide."

"...Being taken SERIOUSLY when someone presents with SYMPTOMS."

"...To be treated with CARE + UNDERSTANDING and not cast aside if there's NO TREATMENT AVAILABLE."

"MEANINGFUL"

"LINKED UP CONSULTATIONS"

"POOLING of INFORMATION"

"...A service that does NOT think TREATMENT is ONE SIZE FITS ALL."

"As a woman who presents as generally fit and healthy, I want to be LISTENED TO When symptoms arise."

"ADMITTING that they DON'T KNOW"

"ACCESSIBILITY & REASONABLE ADJUSTMENTS."

"...A Service that is NEEDS led NOT DIAGNOSIS led."

"Making medicines EASILY ACCESSIBLE to patients when needed."

"FREE ACCESS to medicines relating to the condition."

"TIMELY ACCESS to appropriate services"

Health Assessment, Treatment, Social Support, Financial Support

"COUNCILS Should have a statuatory minimum standard of services.
SCHOOLS Should be funded to supply the level of care required including properly managed transport provision.
HEALTHCARE TRUSTS Should be measured the same for rare disease patients as any other patient, not having different Standards."

"...my son's condition being RECOGINISED by the government."

"ACCEPTANCE of the EFFECT of a debilitating condition in the WORKPLACE WITHOUT it lowering expectations of your ABILITY."

"WE DON'T expect every professional to have in-depth knowledge of the condition BUT We do expect sensible decisions to be made about who is most APPROPRIATE to help us at any given time."

"FINANCIAL SUPPORT Where necessary, especially for items that the general Population DOESN'T WANT OR BELIEVE THEY NEED." e.g. FFP3 respirators

"RESEARCH OPPORTUNITIES for rare CF mutations not eligible for current treatments."

"Being treated EQUALLY and (INCLUSION) for work and all life activities."

"ACCEPTANCE that our SPECIFIC DIETARY NEEDS are a MEDICAL NECESSITY NOT a personal choice."

FRUCTOSE, SUCROSE, SORBITOL

"Add LEARNING DISABILITIES + RARE DISEASES Literature to MANDATORY TRAINING for all hospital Staff."

"Not having to FIGHT for TREATMENT."

"EQUITY aligns closely with the ambitions of the UK RARE DISEASE FRAMEWORK."

"...Not having to REPEATEDLY EXPLAIN to clinicians who I have appointments with ABOUT MY CONDITION."

"EQUAL ACCESS to SPECIALIST CARE for people IN ALL PARTS OF THE COUNTRY."

"Feeling safe that medical Professionals are up to date with knowledge re: my condition."

"ACCESSIBILITY to TOILETING FACILITIES EVERYWHERE must be met for the MOST COMPLEX NEEDS to be met."

"Doctors co-ordinating with each other so treatments don't work against other health problems."

"...HAVING SPECIALISED CARE FOR MY SPECIFIC CONDITION. (There's only one place in the UK which is in England but there's no support in Wales.)"

"POSTCODE MAPPING to check for areas where Patients are not referred into rare disease services."

"A much more effective way of MARKING my MEDICAL RECORDS THAT I HAVE A RARE CONDITION So they can ask how it affects my treatment and what special arrangements are necessary."

"ACCESS to Care CO-ORDINATORS to NAVIGATE a COMPLEX HEALTH SYSTEM."

"...Being BELIEVED my rare illness is NOT anxiety, alcohol or an eating disorder."

"LONGER APPOINTMENTS available to reflect the complexity of living with a rare condition."

"Having the Same SHARED INFORMATION" e.g. between GP + Hospital

"SPECIALISTS doing the TRAVELLING for clinics so that LOCAL PHYSICIANS are UPSKILLED and CONFIDENT in the immediate care of us."

"To not have to WAIT such a LONG time for appointments."

"Readiness of Primary Care Providers to EDUCATE themselves Once they have someone with a rare disease on their books."

"HOLISTIC TREATMENT alongside MEDICAL to include SOCIAL CARE, EDUCATION, NUTRITION, MENTAL HEALTH"

"ACTUAL TANGIBLE SUPPORT Charities etc. have funding for research but very few have on the ground workers supporting those with the actual disease."

"Equal, timely access to treatments for ALL patients REGARDLESS of postcode, speciality hospital or insurance coverage (if not in UK)."

"There should NEVER be a POSTCODE LOTTERY for hospital treatment in-home care or for equipment needed."

"VISIBILITY"

"INCLUSION"

"People need to be EMPATHETIC and realise we may not look ill but that doesn't mean we don't feel unwell. Just because we LOOK NORMAL doesn't mean we aren't STRUGGLING. We are NOT attention seeking. We need to be LISTENED to and taken seriously. I feel unwell 90% of the time, but looking at me you'd never know. We learn to put on a good act because Unfortunately it's what we have to do to SURVIVE."

"...Being taken SERIOUSLY when someone presents with SYMPTOMS."

"ENSURING EVERY OPPORTUNITY IS ACCESSIBLE"

"BROADER TRAINING for non-specialists e.g. GPs, health visitors, Paediatricians"

"EQUITABLE ACCESS for patients with rare diseases to access high quality SPECIALIST SERVICES with HCPs experienced in the rare condition."

"UNDERSTANDING of ALL aspects of MITOCHONDRIAL DISEASE in the same way people understand what having cancer means."

"...Having doctors who are NOT experts in rare diseases TRUST that we sometimes KNOW MORE or can put them in contact with expert doctors."

"...Being ACCEPTED as being rare with no NAMED DISEASE"

"An UNDERSTANDING by the Medical fraternity & wider general community of the CHALLENGES that confront people with a hidden disability."

"To not be FORGOTTEN about."

"Primary heathcare system that ENABLES specialist referrals when suitable, not hinders them."

"DIGNITY"

"To be treated like everyone else DESPITE my disease but to understand that I have some limitation."

"NOT HAVING TO FIGHT FOR SUPPORT THAT MY CHILDREN ARE LEGALLY ENTITLED TO."

"Use of the NHS ENGLAND HEALTH INEQUALITIES TOOLKIT to support."