GROWING INCOME AND AWARENESS

Max Appeal has very low overheads and infrastructure costs, our fundraising ratio is also very low. The vast majority of our costs are associated with engaging with families, researchers, influencers and clinicians.

- Our parents' conference costs approximately £10,000, this provides families with the opportunity to hear speakers from local specialist teams and to meet each other.
- Weekend breaks and family events to provide exciting challenges and a unique opportunity to meet others with the deletion cost around £2,500 per event.
- Our national helpline, 0300 999 2211, costs approximately £2000 a year.
- We make grants of £250 for things like travel costs to parents who may live many hours from the hospital where their child is being treated.
- Our comprehensive information pack for newly diagnosed families costs around £10.

Max Appeal is very grateful to its followers and supporters.

You can help us! Make a donation by sending a cheque to "Freepost Max Appeal", visit our JustGiving page or our web site:

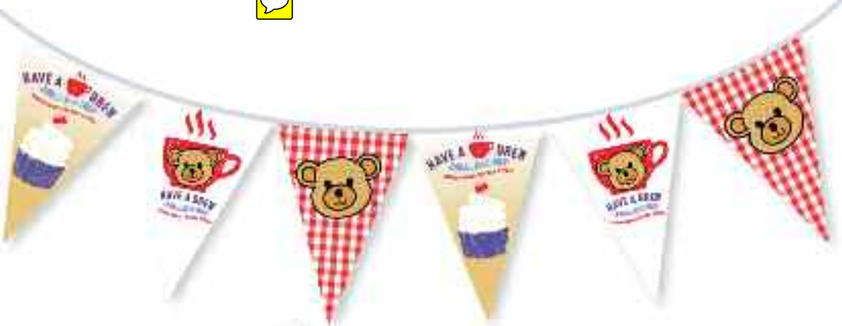
www.maxappeal.org.uk

JustGiving

Does your company have a charity of the year? We would be delighted to present to your board and attend as many of your events as possible. Whether it's "Swapping", golf days, running or even muddy challenges and jumping out of aeroplanes. More sensible people might want one of our "Have a Brew For 22q" packs.

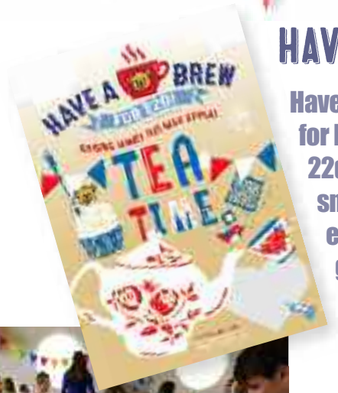
TEXT MAX TO 70660 TO DONATE £5

Every fundraising activity will help us achieve our ambition of a better life for people with 22q11DS.



HAVE A BREW FOR 22Q

Have a Tea Party, raise some money for Max Appeal, raise awareness of 22q conditions and raise a few smiles... this one is a winner for everyone! Apply for your pack of goodies to help you get started?



TEXT MAX TO 70660 TO DONATE £5

info@maxappeal.org.uk
www.maxappeal.org.uk
0300 999 2211
MaxAppealUK

MAX APPEAL
IMPROVING LIVES OF 22Q11 FAMILIES

WELCOME TO MAX APPEAL...

A LITTLE BIT ABOUT US...

Max Appeal is a very small charity, but is one of the largest parent led charities in the world for 22q11DS, a condition that affects around 1 in 1,800 of the population, most of whom remain undiagnosed and not able to achieve their full potential in life.

22q11.2 is like a post code that tells medics that 40 or so genes are missing or duplicated from the long arm of the 22nd chromosome, this is also the underlying cause of DiGeorge syndrome and VCFS. The effect 22q11 Deletion Syndrome (and Duplication Syndrome) has is unique to every individual, from fatal heart defects, catastrophic immune deficiency and severe learning difficulties to mild behavioural problems, speech and language issues and facial characteristics. It is a multi-system disorder and the greatest known genetic risk factor for schizophrenia.

"I would like to take this time to thank Max Appeal because without finding this group I would be feeling so very alone and confused. THANK YOU MAX APPEAL."

Max Appeal was established to offer support to families because this diagnosis is a life changing event for everyone. Max was born on 5th November 1998. He died of overwhelming septicaemia when he was four months old due to complex heart defects combined with severe immunodeficiency problems. Max was a resilient and beautiful baby who endured ceaseless pain during his short life. His parents wanted his life to mean more than his death and so established Max Appeal.

RESEARCH AND INFORMATION

Providing information for families to know what care they should expect from the NHS. We work with over 40 experts and have established the National Consensus on the Diagnosis and Management of 22q11DS. This is now recognised internationally as the 'go to' information for families and professionals. It has been translated into at least one other foreign language. We work with many researchers, hospitals and universities to gain more knowledge of the condition both nationally and internationally. We attend conferences and meetings both to disseminate information, and to engage with professional bodies and organisations.

OUR FAMILIES...

"We had spent years hitting brick walls trying to get support for Hannah – we were at the point where we were literally begging for help. One day in August Hannah decided she could no longer cope– she began to see black bits, couldn't swallow which led to voices telling her to jump off our kitchen roof trying to end her life."

"The moment Harley was born it was clear to me that something wasn't quite right. I was so worried but none of the medical professionals seemed eager to find out why my son was so small and frail. It took years and years of fighting to find the answer. We were finally referred to Geneticist and a simple blood test gave us our diagnosis. It was the missing piece of the jigsaw for me; mystery solved."

"As we approached the last week of our pregnancy we received the bombshell that our little girl appeared to have abnormalities. A test confirmed that Ivy had Di-George Syndrome – a condition we had never heard of – along with that came the devastating news that she had a rare and complex cardiac problem which would see her require open heart surgery throughout her life."

"We appreciate how much Max Appeal have done and all the other 22q families for their eye opening information and experiences we read about on Facebook. Wow, most have had such really difficult beginnings, and all that worry (like us) they must have for the future. I hope my story shows that with the right help and expertise we have in our schools today, that their kids will be able to go on and do truly amazing things and live a good and decent life."

"I want to say a HUGE thank you to Max Appeal for the wealth of information, advice and guidance you provide. We've just had our annual visit with the paediatrician and last time she knew very little about 22q but in the interim seems to have absorbed the extensive info from Max appeal as well as speaking to some advisors. She has put in place all the annual routine assessments (blood tests etc) for Em and seemed something of an expert on her condition. Such a change from last year and she said it was all thanks to Max appeal. So thank you for everything you do, it really makes such a difference."

There are a small number of Multi-Disciplinary Clinics (MDT's) for 22q11.2 at paediatric centres in the UK. Centres include:

Addenbrookes Cambridge, Evelina Children's Hospital London, Freemans Newcastle, Great Ormond Street Hospital London, Noah's Ark Children's Hospital Cardiff, Birmingham Rare Disease Centre. Children affected by 22q11.2 DS are also seen at the Cleft Clinic at University Hospitals Bristol.

A Multidisciplinary Team is a group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients. Multidisciplinary Teams may specialise in certain conditions.

The clinics aims to make sure every child and young person with 22q11 deletion or duplication syndrome receives appropriate care and long term follow up. Children are seen after diagnosis and then at important milestones in their childhood, including transitioning to adult health care. This is important because the needs of children and young people with 22q11 deletion and duplication syndromes can change over time.

If your child has recently received a diagnosis of 22q11.2 deletion or duplication syndrome you may have a lot of questions about what this will mean for them. The teams will have experts who will aim to answer your questions.

Note from Dr.D.S.Kumararatne MBBS; FRCPath; FRCP(Glasgow); FRCP; D.Phil (Oxon). Consultant Immunologist and Director of Cambridge Immunology, Retired Trustee of Max Appeal

Max Appeal was set up in Birmingham, UK (United Kingdom), by a small group of parents whose children were affected by an inherited condition that affected many organs and systems in their body resulting in profound consequences affecting their health and development. At that time this was considered to be rare "orphan" condition, about which little was known.

Showing enormous persistence, gumption and resilience this small organisation sought the help of experts on an international basis to collect and disseminate accurate information about this condition, its diagnosis, its medical and holistic management, its inheritance patterns and the most up-to-date ways of managing the condition, first to parents and families, with an affected individual, and secondly to educate health care professionals involved in the care of those with what is now called the '22q 11.2 deletion syndrome'.

The organisation achieved charitable status in 2001, and all its activities are funded by donations and fundraising activities including varied activities ranging from coffee mornings to running half marathons.

The organisation does not stop at providing and disseminating medical information; it provides holistic pastoral support to affected families and children including participation in fun activities, for the whole family, advice about navigating the benefit system, advice on obtaining special educational support for children with different abilities and so on.

In pursuance of these aims, they have promoted the development of medical centers providing multidisciplinary specialist care within the UK, setting up lobbying activities to improve the care available to affected individuals, by for example, establishing an All-Party Parliamentary group, conducting regular family support and information disseminating days, and sponsoring and funding international scientific meetings on the 22q deletion syndrome.

Max Appeal has set up and maintains a user-friendly, information rich up-to-date website, and has promoted and funded the publication of consensus document describing and setting standards for multidisciplinary best-practice for those affected with 22q deletion. This document has been translated into many languages, and a peer-reviewed version, prepared by Dr. Alex Habel is read widely, and year-on-year receives a high number of scientific citations.

Compared to the information available when Max Appeal was set up, it is now clear that 22q deletion syndrome is one of the commonest inherited developmental disorders, occurring as frequently as the much better-known Down's syndrome.

Given the challenging time caused by the Covid pandemic the unstinting support to parents and families affected individuals provided by Max Appeal has been life affirming. Max Appeal has weathered the difficult financial and social circumstances consequent to the pandemic, due to its good governance, financial prudence, and the hard work of its steering committee of trustees and office staff. Max Appeal is to the best of my knowledge, the largest support organisation for those affected by 22q deletion, and in the true British tradition, punches well above its weight.

SUPPORTING OUR FAMILIES

"Max Appeal have been a God send to me through seeking help with education support, especially when you have strangers telling you they know your child better than you do, ….. I was expecting it to be a nightmare, but when you are armed with facts it makes it much easier."

Our helpline and knowledge gained from supporting thousands of families makes us a unique and powerful source of support from our trained and highly experienced team.

We support people from diagnosis during pregnancy, childhood and adulthood. We offer information and help with schooling issues and help with benefits advice. This can be very difficult especially when more than one member of the family is affected by the condition.

We run special camps for children and young people to take part in activities and meet others with the condition in a supportive and non-competitive environment.

LISTEN, ENGAGE AND INFLUENCE

"Max Appeal listens to families and is the voice of people with 22q11DS."

Growing awareness of the condition is vital. We support hundreds of people each year to attend the International Awareness Day "22q at the Zoo" which provides families with a unique opportunity to meet up and chat in an informal environment.

Max Appeal are members of 22q Europe and we work alongside many other 22q charities around the world, including 22q Society.

We have worked with MPs to secure an All-party Parliamentary Group for 22q11 Deletion to raise awareness with the highest level of decision makers The group is made up of Members of Parliament and Members of the House of Lords covering the whole of the UK

OUR VISION

Max Appeal's vision is of a society where children and adults affected by 22q11.2 deletion are valued and able to fulfil their potential.

OUR MISSION

To enable people with 22q deletion to lead an independent and economically prosperous life as possible with Max Appeal being the voice to achieve appropriate medical care, social support, employment and empowerment for individuals and their families.