



Work of art:
the bunting hangs in
Chalfont St Peter C of E
School, Buckinghamshire

Flying the flags

Wendy Hughes explains how a world record for the longest string of bunting has raised awareness of myotubular myopathy

Staring out over fields at the Glastonbury Festival in summer 2005, Wendy Hughes had an idea. Her friend Anne Lennox had suggested they set up the Myotubular Trust together. Wendy's son Zak, aged 10 and Anne's son Tom, aged 3 have myotubular myopathy and the duo felt that a specific charity could help raise awareness and funds for research into the condition. What they really needed was an attention-grabbing launch initiative.

'I was at the music festival with my husband Simon, Zak and my daughter Sophie. We looked across the fields and saw all these beautiful flags flying,' recalls Wendy. 'I was inspired to start an art project to involve lots of people, and the flags made me think of bunting.'

'Zak likes the *Guinness Book of World Records*, and its entry for the longest string of bunting was just over 1km. Beating that seemed achievable, so we set to work.'

Involving families affected by the condition, schools, brownie and guide groups and famous

names such as Sharon and Kelly Osbourne, cricketer Andrew Flintoff, the Sugababes and Girls Aloud, Wendy asked people to decorate flags and to make a donation to the Myotubular Trust for each one. The project began at Easter this year and was completed in June, with a staggering 6270 flags sewn on to a tape stretching more than 1.5km.

'I think I cried for all eight weeks – it was such a journey for me,' says Wendy. 'The flags contained wonderful messages of support. One little boy stapled a Pokémon card to his flag, another wrote, "Come on, help all those that can't help themselves." It brought out such compassion in people.'

The work now hangs at Zak's school - Chalfont St Peters C of E School, Bucks - but Wendy hopes it may soon be on wider display. 'I'm talking to museums about hanging it as a record of our times. Hopefully, one day there will be cures for genetic conditions such as myotubular myopathy and this project will document a piece of our history.'

'If we reach our target, we'll be able to fund three years of research'

Hope for the future

Funding research is the main aim of the Myotubular Trust and it has already raised £75,000 of its initial £200,000 target.

'The statistics are quite bad for children with the condition,' says Wendy. 'But our scientific advisor, Professor Francesco Muntoni of Imperial College, London, thinks that it is quite likely that stem cell research or drug therapies could play a role in the not too distant future. If we reach our target we'll be able to pay for three years of research.'

Wendy and Anne are in contact with 40 families worldwide and hope to reach many more. 'When Zak was diagnosed at six months old, there was little information available,' says Wendy. 'Now we are able to direct people to other sites that include a lot of information on myotubular myopathy. Setting up this charity is a response to years of pent-up effort. I've been desperate to shout about myotubular myopathy and find other families who probably think they are alone. Together we can hopefully channel our efforts into finding a treatment or cure.'

Now that the Myotubular Trust is established, 'Mrs Bunting' has a full-time job reaching out to others. 'Because Zak is one of the oldest children, I sometimes feel like the mother of all the families. Even though he is less affected than some, they can see how well he's progressed and that gives them hope.'

• For information about Wendy's work and to help in fundraising, visit www.myotubulartrust.com.

• For information about the condition visit www.muscular-dystrophy.org

• Founding Patron: Professor Victor Dubowitz, Emeritus Professor of Paediatrics, Imperial College, London



Get in touch

If you know an inspirational person who should feature on this page, contact Sally Otter at the Muscular Dystrophy Campaign.

Sally Otter

• 020 7819 1814

• sallyo@muscular-dystrophy.org