



THE GM TRUST
DUCHENNE MUSCULAR DYSTROPHY
www.thegmtrust.org

Newsletter Issue 1 - Spring 2009



Duchenne Muscular Dystrophy (DMD) is a progressive and fatal muscle wasting disease. It occurs in 1 in every 3500 male births. It is the biggest genetic killer in the UK. By age 11, most boys are confined to a wheelchair. The average life expectancy for boys with DMD is mid/late 20s. At present there is no cure.

LETTER FROM KERRY AND DORON

Thanks to the incredible and overwhelming support we have and continue to receive, the GM Trust has rocketed into existence since its inception in May 2007. In just over 18 months, the Trust has raised in excess of £1.3 million, is already sponsoring three groundbreaking medical research projects and has been instrumental in forming a delegation that is now in talks with the UK government.

With so much going on, we feel it is a perfect time to update you on progress, both with Gavriel himself and the activities and objectives of the GM Trust.

Gavriel is seven years old now and every day is crucial. 'Never give up' is a phrase that came out of his own mouth and this has now become our motto. He is doing well and in his own way continues to fight the disease with all his might. We must continue to do the same in the only way we can.

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The tremendous success of the GM Trust's inaugural dinner at the London Hilton and the two sponsored bike rides in the UK and in Israel were a credit to the tireless efforts of many. As well as the invaluable funds raised from these events, we take great comfort from the incredible support that is clearly visible on these occasions. We are constantly amazed by the fantastic initiatives that people organise for us - funds from which help us to support our research commitments.

Whilst there is still no cure, we remain completely focused and dedicated to working with scientists globally to support them and speed up their incredible efforts. These are exciting times and we are on the verge of the possibility of putting an end to this tragedy. With your continued care and support we have every chance of doing so within Gavriel's lifetime and saving the thousands of boys who are struck down with this deadly condition globally each year.

Many supporters have commented that they feel they are really part of something special; something that they feel is making a difference. We of course agree. However, we have much work to do and we will stop at nothing to achieve our aim. We do not take your support for granted and we know that we are only as effective as your support will allow. We will continue to update you with details of events, research projects; as well of course with Gavriel's progress.

With your help, we hope to be able to make the tragedy associated with Duchenne Muscular Dystrophy a thing of the past.

With much gratitude.

Kerry and Doron

Trustees and Founders of the GM Trust

GM TRUST UPDATES

APPEAL FILM

The GM Trust's Inaugural Dinner was held on Sunday 10th February 2008 at the London Hilton Hotel on Park Lane. The Appeal Film, fronted by Lord Richard Attenborough, helped us to raise in excess of £600,000! This is enabling us to fund the three vital research projects we have already committed to, as well as allowing us the opportunity of looking into funding further efforts, in order to find a cure for Duchenne Muscular Dystrophy. We are delighted to advise you that after many requests, this short film is now available for viewing on the GM Trust website. If you would like to view it, please email emma@thegmtrust.org to obtain a username and password. It will give you a further insight into our objectives, our current research efforts and offers much more information surrounding DMD and the race against time that we are facing.

GET RUNNING FOR THE GM TRUST!

We need you to take part in our first Community Fun Run Event - come and join our team.

The GM Trust will have places available in the Community Fun Run on Sunday May 24th 2009. Be a part of this community fun day - you can choose to run either 5k or 10k around the grounds of Haberdashers' Aske's Boys School. Organised by the people behind the London Marathon, this promises to be a great event whilst raising vital funds for the GM Trust.

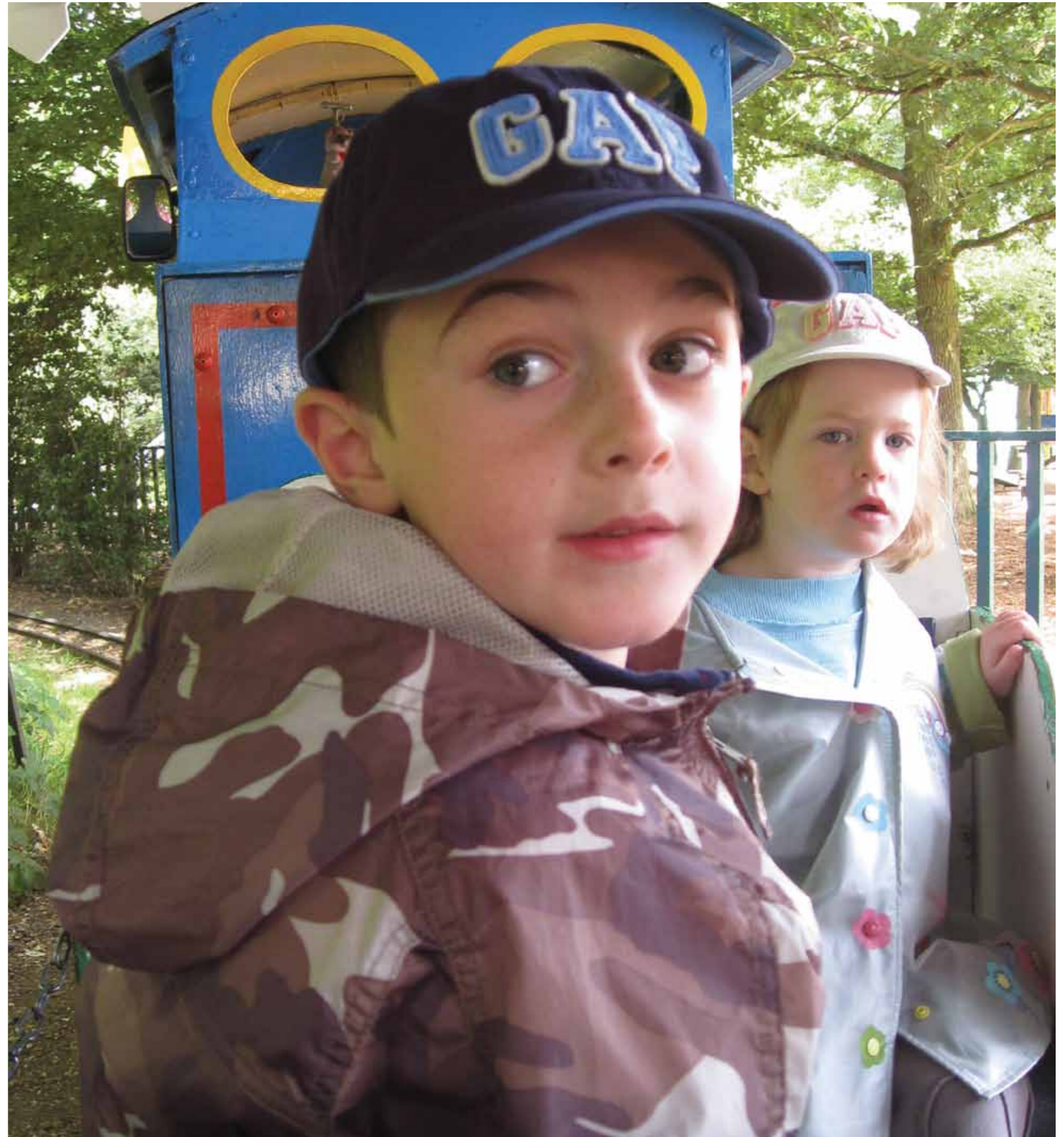
Registration is only £10 (£5 for kids) and there is no minimum amount to fundraise. Every penny you do raise will help us continue our important work.

What are you waiting for? Register at www.communityfunrun.org and choose the GM Trust as your chosen charity.

WEBSITE

Please register your details at www.thegmtrust.org. Be the first to find out about upcoming events, the latest news from the research projects and campaign details.

Do us a favour - Shop till you drop at www.buy.at/gmtrust. All your favourite shops - John Lewis, Amazon, Tesco, HMV to name a few - same prices, same websites, but the GM Trust will get a percentage of your spend at no extra cost to yourself!





WHAT CAN YOU DO TO HELP IN THE WORK OF THE GM TRUST?

The reality is that the GM Trusts' achievements, current and future, are a result of the efforts of many. Over the past year, there have been many incredible initiatives organised by proactive individuals - from mini Marathons to Himalayan Hikes and everything in between. Whilst we can't mention everyone by name we want you to know that we couldn't do any of this without you!

We have a new initiative where people are holding "Parlour Evenings" in their homes and inviting potential donors to come and hear about the work of the Trust and the scary reality that boys with DMD face. We have run these evenings twice so far with each one raising in excess of £5,000. We would like to expand this concept - can you hold one for us? Email dalia@thegmtrust.org or call 07866 417 622 to discuss the possibility of holding a Parlour Evening in your home.

Celebrate with us. Celebrating a special birthday or anniversary? By asking your well-wishers to donate to the GM Trust, you can help further our work in finding a cure for this devastating disease. For more information email dalia@thegmtrust.org.

We are always open to hearing new fundraising ideas. If you have suggestions please email dalia@thegmtrust.org.

To make a donation to support the work of the GM Trust, please go to www.thegmtrust.org and click on Donate. Every penny helps us to continue our vital work.

[DONATE](#)

LINCOLN ABRAHAM FOUNDATION : SUPPORTING THE GM TRUST

We are so grateful to Helen Abraham for selecting the GM Trust to be the current beneficiary of the Lincoln Abraham Foundation. Through her tireless efforts, over £12,000 has been raised for the Trust so far this year. To find out more about the work of her Foundation, visit www.lincolnabrahamfoundation.org

LOBBYING THE GOVERNMENT *

Currently, government interest and funding for DMD is grossly inadequate. In addition to our ongoing fund-raising efforts the GM Trust has now become heavily involved in the essential work of lobbying the government. Our aim is to gain a real commitment from the Government, in terms of raising awareness and allocating sufficient funds and resources for ongoing treatment and research efforts into finding a cure!

In June, the GM Trust took part in a parliamentary lobbying day in London arranged by the charity Action Duchenne. Following which, at the beginning of July, Nigel Evans MP for Ribble Valley further raised the profile of DMD during a televised Parliamentary adjournment debate; where the work of the GM Trust received several mentions. To view the Hansard detailing the minutes from the debate, please contact emma@thegmtrust.org who will be happy to email you the link.

Within a few days of the adjournment debate taking place, the GM Trust was invited to form part of a small delegation to meet with Ann Keen, Parliamentary Under-Secretary of State to the Health Minister. At that meeting, in partnership with Action Duchenne, the GM Trust managed to persuade the government to review their commitment to DMD in terms of treatment centres of excellence available for boys with DMD, as well as to review their budgetary allocation to the global research efforts into finding a cure.

Clearly, it is early days in relation to the governments' real commitment....Actions speak far louder than words. However, progress is being made and we will continue our lobbying efforts alongside our other ongoing activities. If you are interested in finding out how you could add value to our lobbying efforts, whether in terms of lobbying your local MP or other means, please contact emma@thegmtrust.org for more information.

*Please note, the GM Trust has not used any of its funds in these lobbying efforts.



RESEARCH EFFORTS

Under the guidance of the GM Trust Scientific Advisory board, spearheaded by Ronald Cohn, M.D. (Assistant Professor, Pediatrics and Neurology McKusick-Nathans Institute of Genetic Medicine) the GM Trust is now actively supporting 3 global research projects, 2 of which have their base in the UK and now a 3rd project in conjunction with The Nash Avery Foundation, Charley's Fund and CombinatoRX in the USA.

- The first project is the MDEX Exon Skipping project

We are currently funding the first year of a 3 year project, through Imperial College London. This project will test whether it is possible to modify Duplication mutations which is the type of mutation Gavriel suffers from.. The project (requiring a potential contribution of £465,000), involves 3 eminent neuromuscular doctors in laboratories in London, and Australia. Work on this project began in May 2008 and our further funding will be contingent on specific targets and milestones being achieved and subject to approval from our Scientific Advisory board.

- The second project is the Summit Plc - Zebrafish Partnership programme

In October 2007, The GM Trust began funding Summit's preclinical Duchenne muscular dystrophy ("DMD") programme and an innovative early-stage research project called the ZF Partnership.

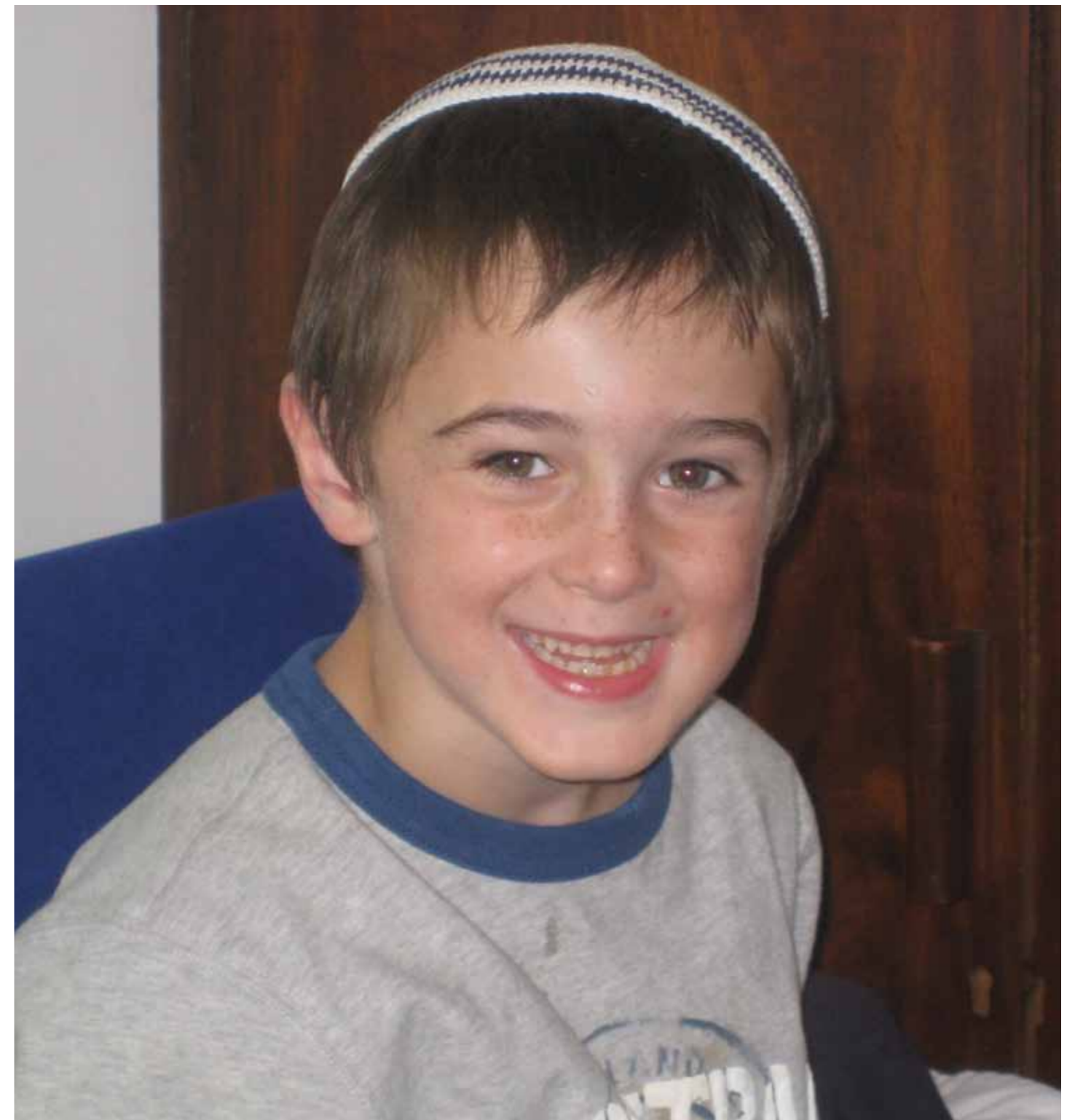
As a result of positive progress with the project, specifically in relation to their Utrophin Drug Screening programme and interest evolving out of the initial support generated by Action Duchenne and The GM Trust, Summit has recently announced that they have entered into an exclusive worldwide licensing agreement with BioMarin Pharmaceutical Inc..

This announcement is a great result for the GM Trust, in that it ensures that work continues on this valuable project, whilst freeing up funds for the Trust to invest in other projects elsewhere.

In addition to these two projects, the GM Trust has recently committed to fund a further project in collaboration with Charley's Fund, the Nash Avery Foundation (both U.S. based DMD charities) and CombinatoRX; a US based pharmaceutical

company are focused on developing new medicines built from combinations of approved drugs. The GM Trust has agreed to invest \$450,000 in addition to the \$3 million already pledged by the two U.S. foundations. Our additional funds will be used to accelerate the programme significantly - precious time in our world!

The Scientific Advisory board is currently reviewing one further grant proposal - results of this review are pending.



THIS NEWSLETTER WAS GENEROUSLY
SPONSORED BY AN ANONYMOUS DONOR



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