



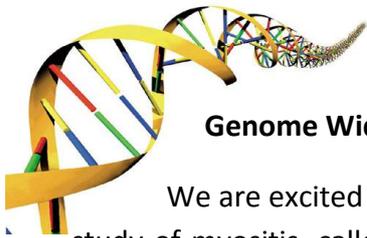
## Hello!

You are receiving this newsletter as you kindly agreed to allow us to collect and store vital information about you or your child's JDM. The JDRG consists of a multi-disciplinary team of doctors, nurses, physiotherapists, scientists and others all working together to research into the rare disease of JDM. We are based at the UCL Institute of Child Health and have a large network of centres throughout the UK that all together form the JDRG.

## Research News

### Euromyositis

We have been working with a group of researchers from across Europe, called EUROMYOSITIS. This group collects data from patients, both adults and children, with myositis (DM and other types of myositis), as we do. We are working to share ideas on the best items of data that all patient research should include, to allow researchers from many countries to work together more closely. The large set of data now available to us in the UK study is very helpful in this project.



### Genome Wide Association Study in myositis

We are excited to have been able to make a very important and large contribution to a world wide study of myositis, called a genome wide association study or GWAS, which includes over 1000 patients with JDM or adult DM. The JDM cases from the UK made a very significant contribution to this study and the results show us that certain genes already known to be involved in autoimmune diseases are important in myositis. This is the largest and first of its kind, anywhere in the world, in myositis and it included patients from 8 countries. We are now doing a sub study within the GWAS data to try to understand why some children get calcinosis in their skin during JDM and others do not.

**THANK YOU FOR CONTINUING TO SUPPORT THESE IMPORTANT RESEARCH STUDIES BY  
BEING PART OF THE JDM STUDY!!**

**369** = number of children now recruited to the cohort study throughout the UK

**11** = number of UK centres that form the JDRG



# The JDRG Website— <http://www.juveniledermatomyositis.org.uk>

The JDRG has an up and running website that gives updated news on research, events, treatment, links to useful websites and more. With help from a rheumatology nurse from Liverpool, we will soon have a section on frequently asked questions (FAQ) where, with help from patients and their families, questions are asked and answered.

We aim to update this section frequently and would be very happy to add your question to the page. Please contact Katie on [info@jdr.org.uk](mailto:info@jdr.org.uk) with your question or any other information you would like added to the website.

The screenshot shows the JDRG website homepage. At the top is the JDRG logo and a navigation menu with items like Home, What is JDM, Treatment, About JDRG, JDRG Centres, Research, Patients / Parents, Funding Bodies, Meetings, Contact, Links, and Website Feedback. The main content area is titled 'Research into childhood myositis' and includes a section on 'Research into childhood myositis' with text about disease prevalence and a research bottleneck. Below this is a section on 'Treatment of juvenile dermatomyositis' with a sub-section 'What Is The Treatment For Juvenile Dermatomyositis (JDM)?' and a list of medications including Methotrexate, Cyclosporin A, Azathioprine, Cyclophosphamide, Hydroxychloroquine, Mycophenolate mofetil, IV immunoglobulin, Plaquemid, Infliximab, and Rituximab. There is also a section for 'Exercise' and contact information for the research centre.

## Teddy-Bo's feeling tired—a story all about living with myositis

Nikki was inspired to write a book for children, their families and friends about living with myositis after Katherine, her daughter, was diagnosed and had to explain what JDM was to not only Katherine, but her family, friends and school.



The book and Teddy-Bo were launched in July at the Myositis Support Group (MSG) annual meeting. Nikki is busy promoting and distributing Teddy-Bo nationally and internationally! If you would like a book and bear please visit [www.myositis.org.uk](http://www.myositis.org.uk) to find out more.

For more information please feel free to contact us: [info@jdr.org.uk](mailto:info@jdr.org.uk) or the JDM research centre on 020 7905 2668.

Cathal Hayes Research Foundation  
Tiny Hearts Research Fund

