LGMD-1D DNAJB6 Foundation
and International Autosomal Dominant Muscular Dystrophy Registry

A 501 (C)(3)

The Newsletter 7/23/2020

Volume: 1 Issue: 3

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Covid 19: what do we know?

(A pulmonary doctor's perspective)

More! But for brevity's sake I will list what I feel are the highlights.

Personal space and fastidious hygiene are important for all age and risk groups. Studies suggest that children are least affected and are not likely to be spreaders. On balance wearing a mask is likely a net positive. Certainly symptomatic and asymptomatic spreaders wearing masks yield the biggest benefit. Well individuals likely have more benefit from a tighter, well filtered mask like an N 95 but this benefit is the hardest to prove therefore the public controversy (See Here).

On the biologic side, Covid 19 is one of many coronaviruses, a family of viruses better known for the common cold. Most parents are frequent participants in this malady from their loving children. Another study (See Here) suggests that even if you have not had Covid 19 or your "antibody" test for Covid 19 is negative your immune system in some people have a collateral immunity from their prior "common colds." This raises hope for vaccine producers that specific immunity to Covid 19 can be induced and have lasting effects.

Many companies are working on a vaccine which will be important for this fall if available by then. Luckily the Covid 19 is not prone to antigenic shift which means it does not put on a new disguise to avoid the vaccine induced immunity.

Covid 19: how do we respond?

(A muscular dystrophy perspective)

Clinical trials have shut down due to the pandemic and researchers have scrambled to provide virtual enrollment with in home assessments. The Foundation has participated in preliminary efforts and has offered financial assistance since this is our charter mission to fulfill the natural history study for LGMD1D as well as other subgroups in need.

Nationwide Children's Hospital in Ohio has been a leader in this effort and their challenges are best appreciated in their recent WEBINAR .

Our other resources can be found at www.lgmd1d.org and our BLOG.

MYOSYND™
The International Registry Process

The Foundation believes that the future of gene therapy is at a fork in the road. The path for gene therapy for autosomal recessive muscular dystrophy is technically different from autosomal dominant muscular dystrophy (AD-MD). Editing at the gene level is a unifying approach for all AD-MD and X linked MD as well. We share this common path. (Advances in CRISPR).

MYOSYND™ was formed as a subsidiary of the Foundation to accommodate all AD-MD, X linked MD groups and individuals interested in forming a larger activist organization. To date we have 80 individuals and a new group, the Myofibrillar Myopathy organization. We encourage not only affected individuals but their families and friends to join as one voice since these conditions are not experienced in isolation.

The "Myopathy Syndicate" looks to the future as a political and medical action group.

Patients register HERE and support persons HERE

We facilitate FREE GENETIC TESTING HERE. See below.

MDA and Invitae: free genetic testing for MD!

Please follow this link

Please note that the Foundation is able to help order this test and have a sputum kit shipped to your home free of charge.

Bonus Section:

Is severe Covid 19 infection a genetic risk and how does it date back to neanderthal man?

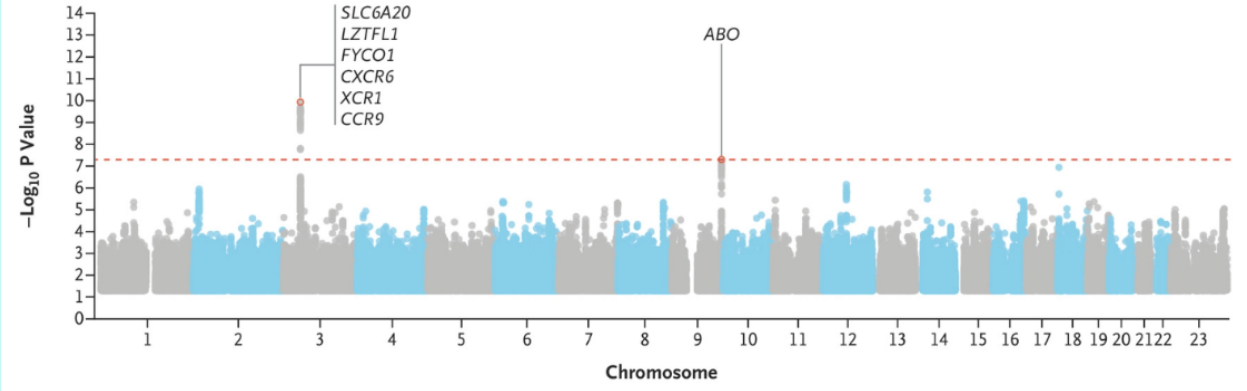
ORIGINAL ARTICLE

Genomewide Association Study of Severe Covid-19 with Respiratory Failure

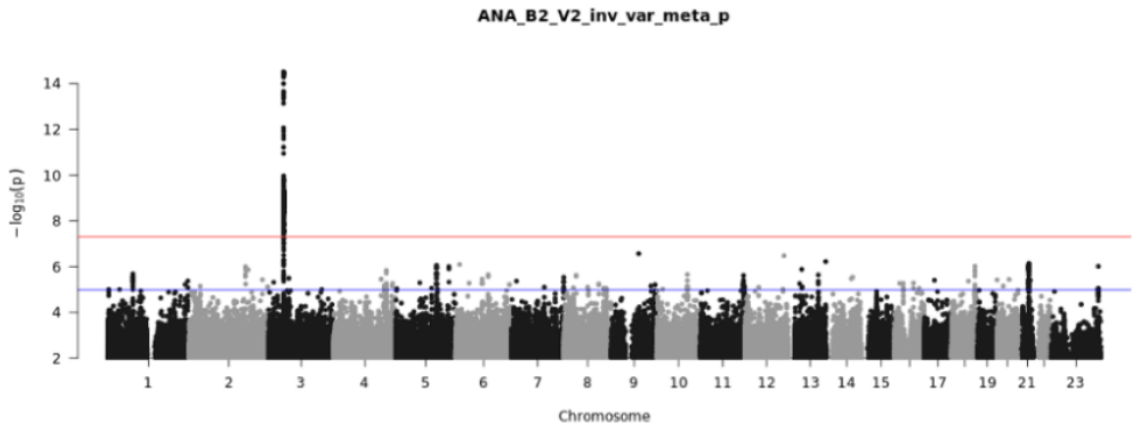
David Ellinghaus, Ph.D., Frauke Degenhardt, M.Sc., Luis Bujanda, M.D., Ph.D., Maria Buti, M.D., Ph.D., Agustín Albillos, M.D., Ph.D., Pietro Invernizzi, M.D., Ph.D., Javier Fernández, M.D., Ph.D., Daniele Prati, M.D., Guido Baselli, Ph.D., Rosanna Asselta, Ph.D., Marit M. Grimsrud, M.D., Chiara Milani, Ph.D., et al., for The Severe Covid-19 GWAS Group*

In this study they found a series of six genes on chromosome 3 with relevant lung immune response:

Spanish and Italian patients with respiratory failure



A second corroborating study for chromosome 3:



Manhattan plot for genome-wide association of 3199 Covid-19 hospitalized cases versus approximately 900,000 population controls. The region at 3p21.31 remains robustly significant but ABO is not significant in this sample. Source: Covid-19 Host Genetics Initiative. (June 2020 release)

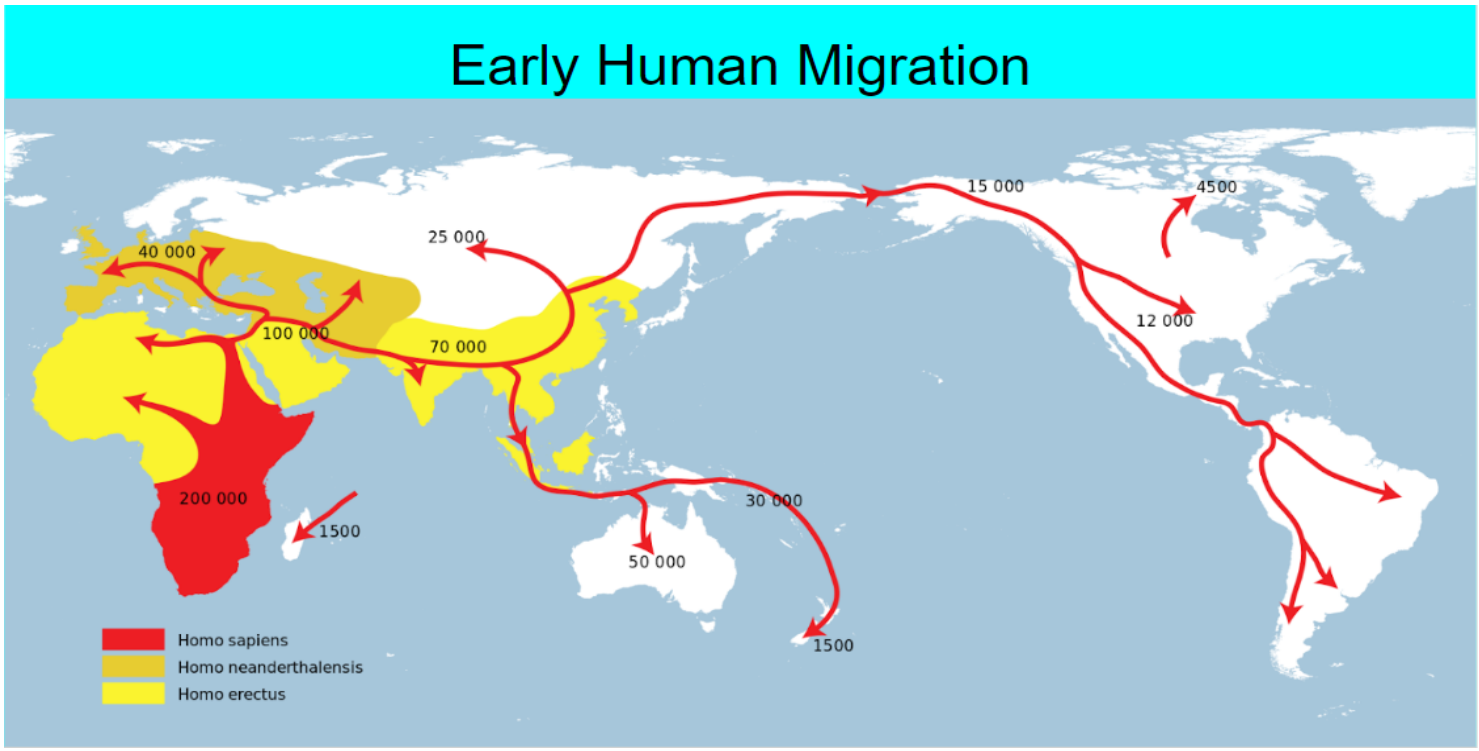
Separate researchers found this gene cluster on neanderthal chromosomes dating back hundreds of thousands of years:

Chromosome 3: Is this a real risk factor dating back to Neanderthals?

The Neanderthal risk haplotype is rare or absent today in most of East and Southeast Asia, and also absent in sub-Saharan Africa. In Europe, the haplotype has a modest frequency of around 5–10%. It also occurs in Native American samples at a similar low frequency. In present-day samples from India, Pakistan, and Bangladesh, the risk haplotype is very common, 40% or more in some places.

See Article

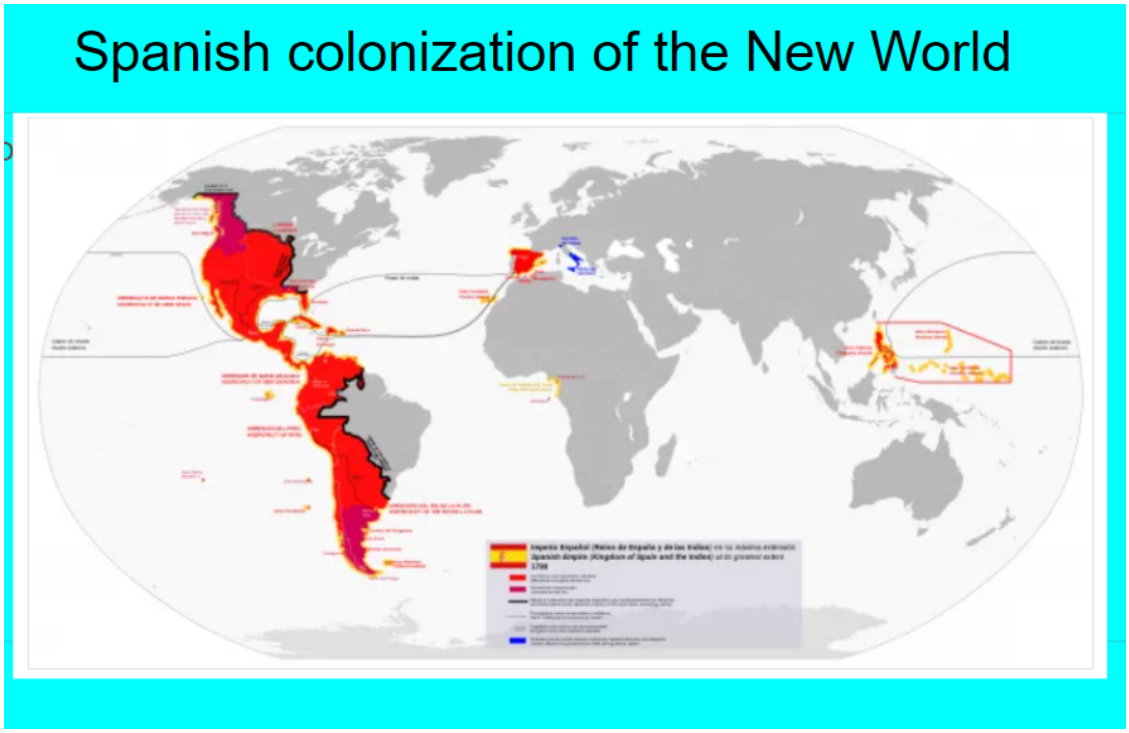
Neanderthals resided mainly in Europe and bordered India:



Johns Hopkins University Worldwide Covid Map: Case Fatality Rate 7/2020

Why are Africa and SouthEast Asia relatively spared?

Why is there such a high fatality rate in regions formerly inhabited by neanderthals and how do you explain the high fatality rate in Central and South America? Could it include new world Spanish and Purtugese migration? Does this explain why Africa and Southeast Asia are relatively spared?



Your comments: wslowery.57@lgmd1d.org

Ways to Give All Year!

1. **OUR WEBSITE** **(a secure site with all the listings below)**
2. **AMAZON SMILE** **(list the LGMD-1D DNAJB6 Foundation for donation with each purchase at no cost to you.)**
3. **PAYPAL** **(Our foundation secure site)**
4. **CREDIT CARD** **(GuideStar charity secure portal)**
5. **VENMO** **(@William-Lowery-24)**
6. **If you are over 72 consider a Qualified Charitable Distribution (QCD) from a traditional IRA and lower that dreadful RMD and avoid that higher tax bracket. Also available to Roth IRA participants.**

See your RMD calculator HERE.
See your medicare income bracket HERE.
See your tax bracket for SS HERE.