

## CM and EDS

A while ago, at TCI, we stumbled on an interesting finding. The incidence of Ehlers Danlos Syndrome (EDS) in our population of CMI patients was way higher than expected. After a couple of statistical calculations, we reached the conclusion that EDS and CMI were closely linked, probably at a chromosomal level. At a second glance, it made sense, since the two disorders are "cousins", since they are both descending from the same fetal structure called mesoderm.

We reached the EDS experts at NIH, and we had a surprise. For a long time, they were puzzled by a rather large number of EDS patients with "strange" symptoms, such as occipital pressure headaches, ringing in the ears, swallowing problems, etc. Does it ring the bell for you Chiarians?

So, TCI and NIH were standing on the opposite side of the same EDS/CMI door.

For the last two years, every CMI patient is also screened for EDS. Given the fact that TCI has the largest ever database of CMI patients, it is logical that this association had to be first seen here.

The patients with EDS/CMI combo are a group apart, with peculiar anatomical, demographic, and physiologic features. Dr Milhorat will present our preliminary data at the upcoming ASAP conference. The complete data will be submitted to an important scientific journal.

The implications of the coexistence of EDS in the surgical management of CMI are striking. The surgical technique in virgin CMI patients (= never operated on before) needs to be modified because of the EDS. A number of post-surgical problems are way more frequent when EDS is coexistent.

For general info about EDS, log on [www.ednf.org](http://www.ednf.org) <<http://www.ednf.org>>

On a personal note, we at TCI are in the progress of gathering the last set of data for the upcoming article (the first draft of which was written in January 2004). A number of patients were called (phone, e-mail) by Ms Denise Petrizzi, our new Nurse Practitioner. Many of these patients did not answer, maybe thinking that the call was a hoax, or just postponing the reply. Please, if you have been contacted, call back Ms Petrizzi (516 570-4417), because the later we get the data, the later the article will be submitted for publication, and the later the other doctors will hear about this important topic.

And before somebody asks me, yes EDS runs in families too, as well as the EDS/CMI combo.

So, for more info, go to the ASAP convention to hear Dr Milhorat talking about this topic.

Thank you,

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The Chiari Institute

PS: The classic EDS/CMI patient is a skinny young woman, with joint hypermobility, and soft skin. Now, I am going out on a limb here, but I do not think that our friend Chip fits he profile. Unless there is a part of him that we do not really know...

Paolo Bolognese, M.D. / April 03, 2005