A NEW ARTICLE ABOUT AN INTERNATIONAL STUDY OF THE HEART DISTURBANCES IN ALTERNATING HEMIPLEGIA OF CHILDHOOD (AHC) HAS BEEN PUBLISHED IN THE SCIENTIFIC JOURNAL BRAIN

Editorial comment and some follow up recommendations from the Coordinator of the Study
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As has always been clear, AHC is a complex condition. The discovery of its genetic cause has started to shed light on how the various aspects of the condition arise. It is important to understand all the different aspects of the condition, so that the best care can be provided to those who have AHC. We know that the main organ of the body involved in the effects of AHC is the brain.

A number of indicators pointed to possible involvement of the heart. One simple, painless and non-invasive way to look at the way the heart is working is the ECG (electrocardiogram, also known as an EKG). We therefore studied the ECG in people with AHC, and compared the findings to ECG records from people with epilepsy but without AHC and to well-known findings from healthy people. We found that some changes in the ECG were more commonly found in people with AHC than in healthy people, or people with epilepsy, suggesting that the changes relate directly to AHC.

These findings are an indication that AHC may affect the heart as well as the brain.

These findings are important, but not a cause for alarm.

We think that the findings should lead to a proper evaluation of heart function in people with AHC, especially in older people with the condition. Such an evaluation could include, for example, review by a cardiologist, perhaps with an ECG, an echocardiogram (a non-invasive, painless, ultrasound examination, to look at the structure of the heart) and longer monitoring of the ECG. Our findings are freely available on the Website of the Scientific Journal BRAIN, and people with AHC, their families and carers might wish to discuss our findings with their specialists. We are continuing to further explore our initial findings so that we can better understand how AHC might involve the heart, and so that we can provide better advice to people with AHC and their families, carers and doctors.

We are putting together more information about the heart in AHC and we are currently running a follow-up study, which any doctors caring for people with AHC are invited to join, by contacting the Coordinator of the Study at ecg-ahc@iahcrc.net.

It is important that we continue to look into how the heart may be involved in AHC, because our initial findings suggest that any involvement may require careful evaluation by heart specialists and may also lead to advice on drugs that should perhaps be avoided in AHC.

Sanjay Sisodiya
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The Article is available as an OPEN ACCESS text on the BRAIN Website at this link.