

Research on Temperature Regulation in Ectodermal Dysplasia

In the Extreme Environments Laboratory at the University of Portsmouth we have been learning from families with ED to find out how living with ED affects temperature regulation. Some have even visited our lab so that we can accurately measure how hot volunteers get when exercising.

From the information we have so far, most ED patients have some, but very limited sweating and certainly not always enough to help cool the body. As well as investigating sweating, we have been looking at methods to cool the body, most practical methods that can be easily performed require a good skin blood flow. In all the people with ED we have tested, they all had very high skin blood flows and so we are able to suggest practical means of cooling, by immersing the hands and/or feet in cool water, or by spraying cool water over their bodies and using a fan to help cool them. We have used these techniques with the British cycling team and also military personnel too.

We are keen to continue finding out more about temperature regulation in people with ED, and are still looking for people to participate in this research and also for non-ED people to take part who are of similar build to a person we have tested with ED.

If you would like to learn more about yourself or a family member and are interested in taking part, we can either come to your home to take some basic measurements whilst you go about your normal daily activities or we can invite you to the lab in Portsmouth to take part in our more in- depth analysis. If you are interested in taking part in the study please contact Heather via email or telephone (heather.massey@port.ac.uk, 07891432744) or diana@edsociety.co.uk or call 01242 261332.

If you wish to attend the laboratory in Portsmouth and are a member of the ED Society you will be eligible to apply to our Support Fund for help with travel and accommodation.

Get too hot?

We are looking for volunteers to take part
in studies to investigate body temperature
control

We are looking for volunteers to take part in our research studies who are
aged 5 to 45 years old



If you are interested in participating or
you think your child may be interested
in participating please contact
Heather Massey

heather.massey@port.ac.uk

or

02392 84 3545



Supporting a normal lifestyle

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