

## Ectodermal Dysplasia No sweat: a hot topic?

Ectodermal Dysplasia has many syndromes, some are well understood with good treatment pathways, whereas other areas have been studied little and so continued support for research is needed to development treatments or advice for patients. Temperature regulation is one area where the ED Society has been leading the way, supporting researchers to help individuals and families who are affected by ED and those who care for patients affected by ED.

At the University of Portsmouth, researchers from the Extreme Environments Laboratory have been putting ED Society members through their paces in their heat chamber. They have seen 18 patients ranging in age from 5 to 45 years old. They aim to establish if members are able to control their deep body temperature when exercising in a warm room (30oC, a warm day in Britain). This may all sound a bit barbaric, but as mentioned in the article 'Can my child play sport' issue 77 (Autumn 2017) of EDlines, physical activity is beneficial for all and children naturally want to be active, so where possible and following the advice in that article we should encourage physical activity or sport.

Anyway, back to the research, in order for the research team at Portsmouth to assess temperature regulation they need to increase deep body temperature to see how the body loses heat. They do this in quite a controlled way to ensure that patients don't become so hot that they become ill but are hot enough to see if a person can sweat, where they sweat from and what areas of the body could be cooled to help reduce deep body temperature if necessary.

During the laboratory testing the staff (Heather, Geoff and Danny) take measurements of deep body temperature, usually from a sensor which is positioned in the ear canal throughout the testing (and wrapped in cotton wool to make it more accurate), skin temperature, skin blood flow using a low powered laser, so there is no need for needles. They also measure sweating using a capsule that sticks to the skin and they take thermal images too. These measurements help to ensure that patients stay within safe limits whilst they are exercising in the heat. These same measurement techniques are also really useful to try out different methods of cooling.

From the research so far, the team have found a number of patients who can sweat enough to regulate their deep body temperature. So, the adage that if you have ED means that you can't sweat is not correct, like many of the conditions associated with ED the severity of the condition may be variable. However, those who have been tested that don't sweat or have very limited sweating still have very good blood supply to the skin, this means that wetting as much of the skin surface as possible will help to remove excess heat. Surface cooling of the hands and feet seems to be particularly effective. In fact, several families arrived with questions about odd behaviours they thought their children had, such as wanting to visit the toilet a lot, but not going to the toilet other than to wash their hands for a long time. In light of what the research team are suggesting, it may be that science is catching up with what patients have been doing all along. Frequent or extended 'hand washing' in cold water will help to reduce deep body temperature. Interestingly, the research team have used the same idea with elite track cyclists who were competing at the Athens and Beijing Olympics, cooling them down in between races.

The research team have also been able to confirm that as children approach and go through puberty their sweating may be more obvious. This may be related to maturation, but also increases in body weight and size which results in an increased sweating rate. If your child is young and you see no evidence of sweating yet, this doesn't mean they won't be able to sweat when they get older. The small size and body mass of a child will mean they can lose heat effectively without sweating or with very minimal sweating, but as they grow and become heavier they may rely more on sweat production to lose heat.

## Supporting a normal lifestyle

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So far, the research is merely catching up with what some patients already do. The advice the researchers are able to give stems from their work with other populations and what families affected by ED have tried. Therefore, it is time to reduce the trial and error for families looking for suitable cooling strategies. It is important that patients affected by ED find cooling strategies that suit their lifestyle, so they will be used when needed; the research team recommend a number of different methods of cooling to try such as staying in the shade, immersion of the hands and/or feet in cold water, wetting shoes and socks to cool the feet, wetting clothes and the skin with water then fanning the body, drink cold or slush drinks. Not all these cooling strategies will be suitable for all patients in all settings, but they are quick, easy and cheap to administer, and one or two may be suitable or adaptable to your situation.

This is by no means the end of the research, the team at Portsmouth are happy to see patients and try to arrange visits during school holidays where needed. If you would like to chat to the research team about the work they have undertaken so far or would like to book a visit, please contact Heather Massey (02392 843545, [heather.massey@port.ac.uk](mailto:heather.massey@port.ac.uk)).

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